

UNIVERSITY OF KWAZULU-NATAL

**Constructions of disability: An exploration of the embodied
experience of blindness**

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Declaration

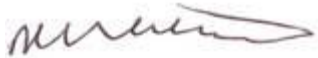
I, the undersigned, hereby declare that the work contained in this thesis, unless specifically indicated to the contrary, is my own original work, and that I have not previously submitted it in its entirety or in part at any university for a degree.

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A handwritten signature in dark ink, appearing to read 'Marietjie Michell', with a stylized, elongated final stroke.

This thesis is submitted with the approval of the supervisor.

Mary van der Riet (PhD)

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Contents

Chapter 1: Introduction	1
1.1 Disability today	1
1.2 The concept of disability	2
1.3 Parameters of the present research	6
1.4. Overview of the present research	7
Chapter 2: Literature review	8
2.1 Introduction	8
2.2 Disability in South Africa	8
2.3 Disability: A multi-faceted concept	13
2.4 The social construction of disability	16
2.4.1 The moral model of disability	17
2.4.2 The charity model of disability	17
2.4.3 The medical model of disability	18
2.4.4 The social model of disability	19
2.5 The embodied experience of disability	21
2.5.1 The psycho-emotional dimensions of blindness	23
2.5.1.1 <i>Hidden assumptions and stereotyping</i>	28
2.5.1.2 <i>Psychic investments</i>	31
2.5.1.3 <i>Living with impairment: The loss discourse</i>	36
2.6 The experience of the body: Accounts of loss and personal suffering in living with impairment amidst a disablist society	41
2.6.1 Self-worth and self-esteem	43
2.6.1.1 <i>Loss of physical integrity</i>	44
2.6.1.2 <i>Social interaction</i>	46
2.6.2 Personal independence	47
2.6.3 Loss of light	48
2.6.4 Loss of environment	48
2.6.5 Loss of everyday skills	49
2.6.6 Loss of mobility	49
2.6.7 Loss of the ease of the written word, and the role of technology	49
2.6.8 Loss of the ease of spoken communication	50

2.6.9 Loss of visual appreciation of the pleasurable and of beauty	51
2.7 Belief system/religion/locus of control	51
2.8 Living with disability: Some reflections of disabled writers	52
2.9 Summary	59
2.10 Aims and rationale	60
2.10.1 Rationale of the study	60
2.10.2 Aims and objectives	60
Chapter 3: Methodology	62
3.1 Research design	62
3.2 Sampling	64
3.2.1 Recruitment	64
3.2.2 Description of the participants	67
3.3 Ethical considerations	70
3.3.1 Autonomy of participants	70
3.3.2 The principle of trust	70
3.3.3 Nonmaleficence	70
3.3.4 Beneficence	71
3.4 Data collection methods	72
3.5 Data storage	73
3.6 Data analysis	73
3.7 Reliability and validity	78
3.8 Reflexivity	80
3.9 Conclusion	82
Chapter 4: Results	83
4.1 Introduction	83
4.2 The responses of others – hidden assumptions	83
4.2.1 Assumptions of inability	84
4.2.2 The assumption that blind people are invisible	86
4.2.3 The assumption that blind people can only do certain jobs	88
4.2.4 The assumption that blind people are not normal	90
4.2.5 The assumption that help is needed	94

4.2.6 Worldview/belief system	95
4.3 The impact of others' attitudes on the emotional well-being of blind people	97
4.4 The personal experience of living with blindness, inclusive of accounts of loss	100
4.4.1 Self-worth and self-esteem	101
4.4.2 Physical integrity/normality	103
4.4.3 Social interaction	104
4.4.4 Personal independence	107
4.4.5 Everyday skills	108
4.4.6 The written word/technology	109
4.4.7 Visual appreciation of the pleasurable and of beauty	110
4.5 Conclusion	111
Chapter 5: Discussion	113
5.1 Introduction	113
5.2 Others' responses to blindness	113
5.2.1 Responses to others' treatment	116
5.3 Belief system/religion/locus of control	118
5.4 Hidden assumptions	119
5.5 Psychic investments	121
5.6 The personal experience of living with blindness	126
5.6.1 The emotional and social well-being of blind people	127
5.6.1.1 <i>Self-concept and self-esteem</i>	127
5.6.1.2 <i>Social interaction</i>	132
5.6.1.3 <i>Personal independence</i>	135
5.6.1.4 <i>Visual appreciation of the pleasurable and of beauty</i>	137
5.7 Conclusion	138
Chapter 6: Conclusion	140
References	146

Appendices	152
Appendix A - Ethical clearance letter	152
Appendix B - Letter to gatekeepers	153
Appendix C - Letter to prospective participants inviting them to submit a short paragraph about themselves	156
Appendix D - Letter to participants	158

Abstract

It appears that disability is not always viewed or treated like other forms of discrimination. Even in South Africa where since the new constitution of 1994 the disability agenda is well established and firmly located within a human rights and development approach, the national psyche, because of a past of institutionalised racism, is still largely aware only of race as an oppressive marker of differentness. Disability is generally not linked with systematic discrimination, disadvantage, prejudice, exclusion and marginalisation. Instead it tends to be viewed in terms of impairment, an individual problem, a personal tragedy, and something that has little to do with society.

This study explored the concept of disability in terms of its meaning, the social construction of the concept, but more specifically, the 'real' experience of disability. The latter includes paying attention to certain aspects of personal experience related to living with impairment, something previously neglected by the social model, the model generally subscribed to today. This model views disability as a form of social oppression, or a constructed category; therefore, scant attention has been paid to the experience of the body in living with disability. The experiences of impairment, embodiment and emotional life have thus emerged as features that need to be included on the agenda for future debate.

In the study, the investigation took place from the perspective of how others' understanding and treatment of blindness affect the lives of blind people. Responses to and treatment of blindness are explored via the accounts of nine blind people. A further focus of the study is the impact that living with blindness amidst a disablist society has on the emotional and social lives of blind people.

The study makes use of a qualitative approach. It employs a largely realist method which reports experiences, meanings and the subjective reality of the participants, and to a lesser extent a constructionist method which examines the way in which events, realities, meanings and experiences are the effects of certain discourses operating within society. The sample consists of nine blind people who made their contributions via emails. The data was analysed using thematic analysis.

It was found that interactions between blind people and the sighted world are largely informed by hidden assumptions. Further, people are unaware of such assumptions as they are largely unconscious and reflective of underlying societal discourses regarding disability, yet they influence the way people view and treat disability. In addition, it was concluded that the attitudes of sighted people regarding blindness and blind people are imbued with psychic investments. It transpired that living with blindness within such a disablist world impacts, in various areas, on the social and emotional well-being of blind people.

Keywords: medical discourse, social model, social construction, embodied experience, loss and suffering, disablism, hidden assumptions, unconscious motivation.

Chapter 1: Introduction

1.1 Disability today

Despite today's intellectual climate of post-structuralism, in which realities such as the self are seen to be socially constructed, and where there is a well-established awareness of racial and gender discrimination as oppressive markers of differentness, the topic of disability is sometimes still either avoided or alternatively treated as if it is synonymous with impairment (Marks, 2001; Watermeyer & Swartz, 2006). Societal discourses of disability as the result of impairment, as a medical problem, and as a personal tragedy underpin, even today, the concept of disability and fundamentally influence the way people understand, treat and experience disability. Many people still see disability as a personal and not a societal problem and generally perceive it as being about specific impairments such as blindness, paralysis and so forth that require various forms of assistance and technology, such as guide-dogs and wheelchairs (Marks, 2001).

In South Africa, as a result of the country's racist past and notwithstanding momentous progress in the disability rights struggle, many South Africans are still largely preoccupied with race as the primary form of discrimination. Consequently, disability is not viewed in the same light; it is not regarded in terms of systematic discrimination, disadvantage, prejudice, exclusion or marginalisation. As suggested above, in the popular mind, it is still largely individualised, not a societal problem and still stubbornly linked to impairment (Watermeyer & Swartz, 2006).

However, if South Africans are serious about democracy, they must begin to move beyond the markers of race and gender, to explore and interrogate further markers of difference, including other forms of discrimination (Watermeyer & Swartz, 2006). An exploration of the concept of disability with the focus on the 'real' experience of disability, that is, what it actually means to live with impairment amidst a largely disablist world (a world informed and directed by prejudice against disability and disabled people), was thus a pertinent and socially relevant area for on-going research endeavours. As personal experience is subjective, the term 'real' is initially used in scare quotes to convey this subjectivity; for most of this thesis, however, the scare quotes should be considered to be implied.

1.2 The concept of disability

The central issue in this study is the meaning of the concept of disability, in this case, what it means for the nine participants to live with blindness amidst a disablist world. Consequently, the overarching research question is: What is the embodied experience of being blind? Subsections of this question are:

- How do assumptions regarding blindness and blind people affect the understanding and treatment of blind people?
- What is the nature and effect of these assumptions?
- How does the experience of living with blindness impact on the emotional and social well-being of blind people?

Furthermore, a particular lens has been utilised in this study in that it has been conducted from the perspective determined by the research agenda, which is to investigate the real experience of living with blindness amidst a disablist world. This includes an exploration of non-disabled people's attitudes in terms of psycho-emotional disablism (disabling barriers which impact on the emotional well-being of people with impairments), hidden assumptions and psychic investments. It is in no way the intention to imply that non-disabled people consciously respond negatively to disabled people; most of what is being explored in this study is on an unconscious level.

The meaning of the concept of disability is examined from both of the perspectives of how society consciously and unconsciously constructs the concept (Marks, 2001; Shakespeare, 1996). This involved looking at how societal discourses regarding the meaning of the concept underpin the understanding and the treatment of disability, and from the embodied or real experience of disability (Hughes, 2002), inclusive of an exploration of the social and personal experiences of living with impairment. Employing some insights of psychoanalysis, attention is also given to unconscious motivation.

An exploration of this kind should commence with establishing what is meant by disability. Determining the meaning of the concept, however, is not as easy as it would appear. Is it impairment, or disability, or is it something in between (French,

1993a)? Oliver (1983) defines impairment as individual limitation and disability as socially imposed restriction (Oliver, 1983). According to French (1993a), the meaning of the concept lies somewhere between impairment and disability; it is not merely impairment that disables and also some aspects of living with a disability amidst a disablist world are difficult to regard as entirely socially produced or amenable to social action (French, 1993a; Watermeyer, 2013).

By means of seeing which model illuminates or obscures part of the data and how each model does this, this study examines the medical model, which links disability with impairment (Marks, 2001), and the social model, which views it as a form of social oppression or as a constructed category (Barnes, Oliver & Barton, 2002; Marks, 2001; Shakespeare, 1996). In addition, this study examines the embodied (the real) experience of disability, with the emphasis on some psycho-emotional dimensions of blindness, that is, experiences that influence the social and emotional well-being of blind people (Thomas, 2002).

The attitudes of non-disabled people to disability are investigated from the perspective of the participants because it is argued in this study that most interaction between the blind and the sighted world is largely underpinned and informed by hidden assumptions. As these assumptions are seen to be at least partially unconscious, those holding them are often not even aware of them yet they are nevertheless revealed in the way blindness and blind people are treated (Morris, 1991). For this reason, the study focused on the participants' accounts of their treatment by others.

Some theorists such as Marks (2001) have further argued that the attitudes of non-disabled people are imbued with psychic investments. People habitually repress certain existential anxieties, and disability and disabled people may come to represent these feelings. Consequently, others' responses to disability and disabled people can be seen as a reflection of these unconscious fears and fantasies which are projected onto disabled people, who are then experienced as threatening or pitiful, and who are avoided because they serve as awkward and unsettling reminders to non-disabled people of their own unconscious fears (Marks, 2001).

Moreover, because these feelings are experienced on an unconscious level, people are generally unaware, or only partially aware of them, yet such feelings influence the way they treat disabled people (Watermeyer, 2006). According to Marks (2001), there is, as a result, an uncomfortable silence around disabled people or the topic of disability. She provides an example of this uncomfortable silence: "As in a child told not to stare, the desire to look, combined with the fear of something unthinkable, yet intriguing, creates a heady mix of prurience, insecurity and avoidance of the subject" (Marks, 2001, p. 89).

Not only might such an uncomfortable silence lead to the conscious or unconscious avoidance of the topic of disability or of disabled people, but also to the possible rejection, exclusion and eventual marginalisation of such people (Morris, 1991). Therefore, this study aims partly to raise awareness concerning the plight of disabled people within society, whilst at the same time, providing a safe space for participants to share with others a personal account of living with blindness within a disablist society. It is hoped that this study will contribute to the greater body of research on the topic. Even though it has grown dramatically in the last few years (Marks, 2001), the discipline of Disability Studies has not yet received its full quota of academic attention (Grue, 2011), particularly in South Africa with its lingering preoccupation with race (Watermeyer & Swartz, 2006).

In this regard, the 1997 government White Paper on the Integrated National Disability Strategy (the INDS) called for research to promote the rights and participation of disabled people in South Africa (Howell, Chalklen & Alberts, 2006). This led to a major book, supported by the Disability Movement in South Africa, being published in 2006. The book, *Disability and social change: A South African agenda*, was edited by Brian Watermeyer, Leslie Swartz, Theresa Lorenzo, Marguerite Schneider and Mark Priestley, and was compiled within the Child, Youth, Family and Social Development Research Programme of the Human Sciences Research Council. This book issues South Africans with a powerful challenge to intensify efforts to make the provisions of the Constitution real for all South Africans. It calls on South Africans to build a more inclusive society; to continue thinking about and researching the rights of disabled people; and to take on board the slogan of

Disabled People South Africa, 'Nothing about us, without us!' (Watermeyer & Swartz, 2006).

This inspired the researcher, who herself is a blind person, to make her own contribution, hopefully contributing in some way towards enhancing the position of disabled people in South Africa. With this study, the researcher hoped to facilitate a better understanding of what it means to be disabled, for the participants, as well as for others in society. On the other hand, the researcher intended to enrich and empower the lives of the participants by making them aware of the strengths which could be gained from being part of a collective struggle which attempts to make fundamental challenges to society. The researcher wanted to draw to their attention the fact that disabled people can assert the importance of their experience for the whole of society, and insist on their right to be integrated within their communities. By claiming their own definitions of disability, they can choose to take pride in themselves, in what they are, and in their difference, placing a more positive value on their bodies, themselves and their lives (Morris, 1991).

The intention further was to contribute to the process of negotiating a way for people living with impairment in a disablist world to acknowledge having experiences that influence their psychological and emotional well-being, including possible experiences of loss and personal suffering, without being defined by these experiences. It is just as important for blind people, as for anyone else to have a voice, to be heard, to be understood, to be known and to share their meanings with others, without facing the possibility of having their identities tarnished thereby. Consequently, one of the aims of this study was to allow the participants to be heard and to be understood. The study attempted to provide a safe space for the participants to reveal and share a personal experience of living with blindness amidst a disablist society (Watermeyer, 2009).

On the other hand, the idea was for anyone who reads this study to vicariously experience the challenges disabled people may encounter in their everyday lives and, in so doing, to provide a lens through which such readers can view the world of the disabled person and consequently gain a better understanding of disability (Creswell, 2009).

1.3 Parameters of the present research

There is a substantial body of research documenting the path of disability issues via traditional medical approaches which link disability to impairment (Marks, 2001), through to the social model of disability, which sees disability as a form of social oppression and as socially constructed (Marks, 2001; Shakespeare, 1996). However, what still need interrogation and exploration are the embodied experience of disability, that is the experience of living with disability on a day-to-day basis, (Hughes, 2002; Marks, 2001), as well as the role of unconscious motivation in interactions between disabled and non-disabled people (Marks, 2001; Watermeyer, 2006; 2009). To this end, the study focused particularly on these two aspects of disability.

The embodied or real experience encompasses the emotional and social aspects of living with blindness, inclusive of possible accounts of loss and suffering and the impact of others' attitudes (Morris, 1991; Reeve, 2012; Thomas, 2002; Watermeyer, 2009). Furthermore, any exploration of others' attitudes to blindness should at least touch on the issue of disablism (prejudice against disability). In fact, Watermeyer (2013) goes as far as to suggest that a full understanding of attitudes concerning disability is central to any attempt to change and reformat society which in his opinion is permeated with discrimination and exclusion (Watermeyer, 2013).

Overall, the study aimed to explore how assumptions regarding blindness and blind people affect the understanding and treatment of blind people. The nature and effect of such assumptions were examined. In addition, the study also investigated the way the experience of living with blindness, amidst a world which is to a great extent informed and directed by disablism, impacts on the emotional and social well-being of blind people.

The research utilised a qualitative, largely realist approach which reports experiences, meanings and the reality of the participants, and to a lesser extent a constructionist method which examines the way in which events, realities, meanings and experiences are the effects of certain discourses operating within society. The data was collected from the nine blind participants via email contributions.

1.4. Overview of the present research

After introducing the topic, this thesis will commence with an outline of the relevant literature pertaining to the meaning of the concept of disability, starting with an overview of how society consciously and unconsciously constructs the concept of disability and demonstrating a progression towards reincorporating the extra-discursive, the real, into the experience of disability. An understanding of the role others' assumptions play in the treatment of blind people and its impact on such people, others' unconscious motivation, as well as some accounts of blind people's personal experiences in living with impairment, is developed (Chapter 2). Thereafter in Chapter 3, the research design and methodology will be explicated, with particular emphasis on ethical issues. In Chapter 4, the results of the research project are presented. A discussion and interpretation of the analysis of the results is undertaken in Chapter 5. In Chapter 6, conclusions are drawn.

Chapter 2: Literature review

2.1 Introduction

This study explored the meaning of the concept disability, in this case blindness, in terms of the social construction of the concept, the embodied experience, that is, the real, personal experience of living with blindness, the impact of living with impairment and the role of unconscious motivation. The study was done partly towards raising awareness concerning the situation of blind people within their communities, and towards drawing academic attention to the topic of disability as a potential oppressive marker of differentness (Watermeyer & Swartz, 2006). Further, the study attempted to provide a space for the participants to safely share personal experiences relating to living with blindness amidst a disablist society.

The meaning of the concept disability was examined from the vantage point of how society consciously and unconsciously constructs the concept of disability (Marks, 2001), as well as from the individually embodied experience of disability (Hughes, 2002). This approach straddles individual and communal/post-modern approaches, whilst moving towards reincorporating the extra-discursive, which are the real experiences into the experience of disability (Nightingale & Cromby, 1999). The theoretical exploration in this study was based mainly on what has happened with disability issues in England because of the huge influence it has had worldwide, including within South Africa. However, in order to contextualise this study, a brief look at the disability scene in South Africa is included.

2.2 Disability in South Africa

In South Africa today the disability movement is well-established, located within a human rights and development approach, and firmly rooted within a close alliance with the current ANC government (Watermeyer & Swartz, 2006). The last 20 years or so, however, have been momentous and particularly significant in the history of the disability rights struggle. Since 1994, new policy and a new legislative framework have developed in South Africa. The efforts of South African civil society disability organisations have greatly contributed to these developments (Howell et al., 2006). Under apartheid all disabled people, black and white, were discriminated against and marginalised because of their disability. Such people in general were seen as people

who were sick or in need of care, rather than as equal citizens with equal rights and responsibilities (Howell et al., 2006).

The experience of disability was, however, slightly different for black and white. For white disabled people, it was largely a matter of discrimination on the basis of disability, whereas for many black disabled South Africans, the policy and practice of apartheid served to compound their experience of discrimination, indignity and poverty. They battled on a daily basis to cope with the deprivation and violence of the apartheid system, a struggle made worse by their disability. Consequently, they were strongly influenced by the inequalities and oppression of the apartheid system, making the overcoming of political and economic oppression an integral part of the liberation of disabled people. Thus the struggle had to be against apartheid as well as against how people understood and responded to disability (Howell et al., 2006).

In 1994, with the new constitution, for the first time in the country's history, basic human rights were extended to all citizens. Giving all South Africans the right to vote, the constitution further outlawed unfair discrimination. Further, equity among all South Africans was promoted by recognising the need to implement specific measures that would address the disadvantages that particular groups of people, including disabled people had experienced (Howell et al., 2006). South Africa's new constitution is therefore especially important for disabled people; it is very clear on the issue of disability and the need to eradicate any form of discrimination on the basis of disability (Matsebula, Schneider & Watermeyer, 2006).

After its election in 1994, one of the most important tasks that the new democratic government undertook was setting up the Reconstruction and Development Programme (RDP) situated in the President's Office. In line with the argument that disability is a human-rights and development issue, the disability-rights movement lobbied for establishing a Disability Desk within the RDP which would create a government structure to address disability issues throughout all ministries (Howell et al., 2006). Consequently, the National Office on the Status of Disabled Persons (OSDP) was established within the Presidency, and within the Premier's office in each of the nine provinces. The process of establishing disability desks and units in local municipality offices is currently still ongoing (Matsebula et al., 2006).

Because of its very location in government, and with an aim and mandate to mainstream disability issues into all sectors of society, the OSDP was one of the most important disability-related institutional mechanisms. In consultation with all the main players in the disability sector, it developed a framework for an Integrated National Disability Strategy. In November 1997, the White Paper on an Integrated National Disability Strategy for integrating disability issues into all aspects of government functioning (INDS) was published by the government (Howell et al., 2006). The OSDP ceased to exist when the Department of Women, Children and People with Disabilities was instituted in May 2009. Subsequently, there has been a further change, with disability now being overseen in the Department of Social Development.

Regarding legislation relating to disability discrimination, unlike the majority of countries, South Africa has included disability issues within its constitution, attempting to ensure that no one in South Africa may be discriminated against on the basis of disability. This has led to a number of related pieces of legislation being promulgated, which target disability discrimination specifically. These include the Employment Equity Act, No. 55 of 1998, and the Promotion of Equality and Prevention of Unfair Discrimination Act, No. 4 of 2000 (Matsebula et al., 2006).

The Employment Equity Act prohibits unfair discrimination against disabled people, and also provides for affirmative action measures to promote employment equity. In terms of the Act, all legal entities that employ more than 50 people must submit Employment Equity Plans to the Department of Labour, showing how many people with disabilities are employees and what positions they hold (SAHRC, 2002, in Matsebula et al., 2006). This is in recognition of the fact that, due to ignorance, fears and stereotypes, disabled people are unfairly discriminated against in society as well as in employment. Consequently, disabled people often find themselves unemployed or in low status jobs earning lower than average remuneration (Matsebula et al., 2006).

The Promotion of Equality Act is an extension of the constitutional provisions prohibiting unfair discrimination and guaranteeing equality before the law. Significantly, the Act rules that the promotion of equality is the responsibility of

persons operating in the public and private domains' (SAHRC, 2002, in Matsebula et al., 2006). These two laws provide a good platform from which to promote the human rights of disabled people in South Africa (Matsebula et al., 2006).

However, notwithstanding this focus on rights and changing conditions for disabled people, long-held attitudes are not so easily altered, as the personal accounts of the participants in the present study confirm. Furthermore, there is also a definite need to move from policy development to policy implementation (Matsebula et al., 2006; Rule & Modipa, 2012). There exists a real risk that the strong impetus towards transformation may dissipate somewhat due to insufficient follow-through with implementation programmes.

Whilst it is generally agreed that the setting up of the OSDP reflected a major achievement for the disability-rights struggle, it is also true that there were weaknesses in the Office. Howell et al. (2006) comments that these were largely of a structural nature; the OSDP could only influence and monitor policy in key areas and did not have direct responsibility for the implementation of policy – this is the responsibility of each line-function department (Howell et al., 2006).

Furthermore, in order to keep abreast of the direct concerns of the majority of disabled people, it would be ideal for such an office to maintain strong links to civil society organisations. Problems arose in respect of this aspect. For example, there was the perception within the disability movement that the OSDP would be a direct service provider to disabled people. However, this did not match the OSDP's actual aim, which was facilitating disability integration into government policy development and implementation, and this mismatch led to dissatisfaction and some tension between organisations of disabled people and the OSDP (Matsebula et al., 2006).

Various implementation issues relating to, for example, accessing public transport, information, houses and public services are seen as at the heart of many problems still experienced. Many disabled South Africans feel that the changes taking place have made no real difference to their daily lives. The 2001 census revealed that in South Africa, people with disabilities constituted 5% of the population, but for example, in the area of education alone, disabled people were disproportionately

represented in the category of people with no education (10.5%), and under-represented in successively higher levels of education: primary (5.2%), secondary (3.9%), and higher (3.0%) (Statistics South Africa, 2005, in Rule & Modipa, 2012). Consequently, there is a significantly larger percentage of the adult population of disabled people that is illiterate or semi-illiterate than the general adult population. Many black disabled people either never attended school or dropped out at an early stage on account of Apartheid as well as discrimination against people with disabilities (Rule & Modipa, 2012).

The point was powerfully borne out at the 2001 congresses of Disabled People South Africa (DPSA) and Disabled Children's Action Group (DICAG). Enormous backlogs and lack of real improvements in accessible public transport, housing, health services and social security were noted. Continued difficulties in accessing health, welfare and education services for their disabled children were reported by parents (Howell et al., 2006).

The continued exclusion of disabled people from accessing basic socio-economic rights is further exacerbated by the high levels of poverty that still confront the majority of disabled people in South Africa. Such barriers still exclude many disabled people from opportunities, including employment and equal participation in society (Howell et al., 2006).

Material interventions such as legislation are important in creating a framework within which to address disability issues. Yet this is not sufficient; implementation is problematic (as mentioned above); in addition, attitudes on the ground continue to impact negatively on the lives of disabled people. Laws alone are not enough. With regard to the effectiveness of material interventions such as legislation, from a development studies perspective, Coleridge (1993) rejects the view that material interventions can change human nature with respect to the treatment of disabled people. This may be applied to legal mechanisms such as the USA's Americans with Disabilities Act (1990), Britain's Disability Discrimination Act (1995), and many similar policies such as South African legislation in respect of disability.

While provision of basic needs such as food, shelter and health care is of course essential, Coleridge (1993) takes issue with viewing 'development' as limited to this. He writes:

The problem lies in the fact that such needs are passive: if these needs are met, so this approach asserts, then 'development' has happened. But there are other needs which are just as basic: the need to be creative, to make choices, to exercise judgment, to love others, to have friendships, to contribute something of oneself to the world, to have social function and purpose. These are active needs; if they are not met, the result is the impoverishment of the human spirit, because without them life itself has no meaning. (Coleridge, 1993, p. 213)

Notwithstanding all the remarkable advances in South Africa, the ongoing struggles for equality, dignity and access for many disabled South Africans remain real and must be acknowledged. Furthermore, in order to facilitate an improved mutual awareness and respect, there are still gaps in the understanding of the experience of disabled people which warrant investigation. For example, it has been suggested that in order to change and reformat a society which remains permeated with discrimination and exclusion, a full understanding of attitudes concerning disability is crucial (Watermeyer, 2013).

The struggle is far from over, as attitudes to disability have shown themselves remarkably resistant to change (Rowland, 1985), and as, particularly in the developing world, disabled people remain the poorest of the poor (Meekosha & Soldatic, 2011). Many battles are still to be fought before disabled people in South Africa occupy their equal and rightful place in society (Howell et al., 2006).

2.3 Disability: A multi-faceted concept

Disability as a phenomenon is emotive and multi-layered in nature, consisting of culture, politics, self and body (Watermeyer, 2013). The concept comprises many aspects and angles; it is consciously and unconsciously constructed (Marks, 2001; Shakespeare, 1996). Thus, societal discourses underpin the understanding and the treatment of disability, unconscious motivation plays a role, and it includes the embodied or real experience of living with impairment as well (Hughes, 2002).

In a move towards a more mature, nuanced understanding of the concept, it is also necessary to make space for an understanding that conceives of disability lying somewhere between social restriction and impairment. Some of the most vexing problems experienced by people with certain impairments are difficult, even impossible, to solve by social manipulation (French, 1993a). Yet again, these issues can only be explored in terms of the meaning of disability; if disability is viewed as impairment, 'individual limitation' (medical model) or conversely as 'socially imposed restriction' (social model) (Oliver, 1983), then not being able to see or not being able to walk are impairments, but lack of access to written information and lack of mobility are disabilities (French, 1993a).

The implication of the latter statement is that disability is socially created and could be solved by adjusting the social and physical environment to ensure that the needs and rights of people with impairments are met, rather than attempting to change disabled people to fit the existing environment. Such changes to the environment would include, for example, providing text to voice devices, more bleeper crossings or more electric wheelchairs, wider doorways and more ramps and lifts. Disability is viewed as a problem located within society (social model), and is not placed within individuals who happen to have impairments (French, 1993a).

French (1993a) mentions various social problems encountered as a visually impaired person, which are difficult to regard as entirely socially produced or amenable to social action and which according to her, impinge far more on her life than "indecipherable notices or the lack of bleeper crossings" (1993a, p. 19). Such problems she says include inability to recognise people, and not being able to read non-verbal cues or emit them correctly (French, 1993a).

Furthermore, she says, often a social remedy does not necessarily eliminate disability, for example, giving adapted computers to blind people may enable them to do a job which otherwise they could not do, but it does not transform them into sighted people. Many of the barriers they face are socially produced, but to argue that sophisticated equipment and alternative working methods eliminate these barriers is going too far; indeed, however, they may well exacerbate them by removing human help (French, 1993a). She says:

On occasions I have made an effort to find social solutions to some of these problems ...my attempt to manipulate the social environment was not a success, and although my situation does give rise to social isolation, I do not feel inclined to repeat the experiment. The difficulty I have described is not entirely due to my impairment, for it involves other people's responses, but neither is it easily modified by social or environmental manipulation; it occupies a middle ground. (French, 1993a, p. 18)

As the concept is clearly multi-faceted and produced by several factors, highlighting any one facet or factor or adopting any single approach or viewpoint will tend to lead to uncritical assumptions about what disability is (Marks, 2001). The focus cannot solely be on “disabled people as individuals with damaged bodies (medicine), emotional difficulties (psychology), stigmatised identities (social psychology) or as individuals who represent challenges to public policy (economics, politics and sociology)” (Marks, 2001 p. 12).

Accordingly, a multi-dimensional approach is needed, integrating an understanding of the social construction of the concept, the embodied experience of disability, which includes a personal experience of living with impairment (Carroll, 1961; Hughes, 2002; Marks, 2001; Watermeyer, 2009), and also the role unconscious motivation plays (Marks, 2001; Watermeyer, 2006; 2013). The idea behind such a multi-dimensional approach is to attempt to bridge the gap between the “personal and the political, the internal and the external” (Marks, 2001, p. 12) experiences of disability, and move towards a deeper, critical understanding of disability (Marks, 2001).

It comes as no surprise, however, that such an integrative approach is open to all kinds of criticism. On the one hand, for social model theorists, any focus on impairment could be seen as pathologising and oppressive to disabled people, giving succour to medical approaches. On the other hand, those in the medical and rehabilitative camps may see social model theorising as being 'unrealistic' or uncaring about the real problems faced by many disabled people, especially in terms of the issue of actually living with impairment. Further, psychoanalytical writers may accuse social model theorists of not coming to terms with problems and of denying

loss or difficulty, whilst social model theorists may see psychoanalysis as being part and parcel of the medical model (Marks, 2001). Notwithstanding the possible criticisms of such an integrative approach, hopefully the insights brought by such an approach may be of some value in deepening a critical understanding of the many angles and facets of the concept of disability.

2.4 The social construction of disability

As a first step in such an approach, it is argued that the meaning of disability is inextricably linked to how society consciously and unconsciously constructs the concept of disability and is interwoven with individual and communal/post-modern approaches. In order to provide the backdrop for the study, the concepts of modernism and post-modernism as world views are briefly reviewed in relation to the meaning of disability.

According to Hurd (1998, in Archer, 2010), the word modern refers to a specific period of time, roughly from the 1870's through to the mid-1960's and to the range of cultural ideas, beliefs, and artefacts that people generated during that period. Modernism claims that science and the arts could explain the self, human happiness and even the world at large, presupposing an understanding of human identity and self that is unified, coherent, and autonomous. 'Man' is seen as a thinking being, capable of rationally perceiving, knowing, and conquering the world (Hurd, 1998, in Archer, 2010). Post-modernism shatters and subverts each of these notions, perceiving the world as "a large network of interconnected but meaningless components and experiences" (Frosh, 1991, p. 282). Post-modernism proposes relativity of meaning, the impossibility of ever comprehending such meaning, uncertainty, chance, marginalisation and fragmentation (Frosh, 1991).

Regarding identity, in contrast to the modern unified self, in post-modernism there is a dissolving and fragmenting of the self, shrouding the concept self in uncertainty (Frosh, 1991). According to Marks (2001), the concept of wholeness is thus uncertain and called into question, therefore implying that the concept of the broken body also becomes of theoretical interest (Marks, 2001). With this in mind, the concept of disability is central to this study. Towards exploring this concept, initial

questions to be asked are: Who is disabled? And: What is understood by being disabled?

Since time immemorial, there have always been disabled people, and they have had a presence in all societies. Within Western culture, such people have been associated with a broken, dysfunctional and damaged existence, with the cause of their widespread economic and social deprivation primarily to be found within the individual and their impairment (Barnes et al., 2002; Marks, 2001). As a result, the social and economic destiny of disabled people tended to be understood as the logical consequence of impairment of the body (Barnes et al., 2002). In order to address the questions above, different models of disability are mentioned: a moral model, a charity model, a medical model and the social model of disability.

2.4.1 The moral model of disability

In terms of this model, disability is linked to sin, wrong-doing and shame, with the disabled person being held responsible for what he or she is. Further, the family of the disabled person is often also regarded with suspicion. Neither government nor society is concerned with the problems faced by the disabled (Bhanushali, 2007). The moral model of disability is historically the oldest, and is less prevalent today. There are, however, even today some cultures that still associate disability with sin and shame. Also, disability is often associated with feelings of guilt, even if such feelings are not essentially religious (Kaplan, 1999).

For the disabled person, this model is particularly onerous, being associated with shame on the whole family. Families have been known to hide the disabled person, keeping them out of school and excluded from any chance at having a meaningful role in society, resulting in general social ostracism and self-hatred (Bhanushali, 2007; Kaplan, 1999).

2.4.2 The charity model of disability

The charity model embodies notions of charity and benevolence in relation to disability, rather than those of justice and equality. Entitlement rights are substituted with relief measures. In terms of this model, disabled people are viewed and treated as helpless victims needing care and protection and are excluded from the social

arena as well as from the public domain; they are also excluded from employment and services such as mainstream education. This creates an army of powerless individuals, without any control or bargaining power, depending either on state allocated funds or the assistance of benevolent individuals (Bhanushali, 2007).

2.4.3 The medical model of disability

The medical model sees disability in terms of impairment, regarding the personal, social and economic difficulties associated with disability as located within the individual (Marks, 2001). Society is seen as having no real responsibility towards disabled people because disability is basically a personal problem. The medical model is more than a mere model, as it represents a societal discourse, the basic framework that supports ideas about disability and is woven into the very fabric of society, underpinning the concept and fundamentally influencing the way people understand, treat and experience disabled people.

Even today, most people link disability exclusively with specific impairments, and perceive of disability as a personal and not a societal problem (Marks, 2001). Notwithstanding finding ourselves in an intellectual climate of post-structuralism, in which realities such as the self are seen to be socially constructed, and an awareness of racial and gender discrimination has steadily grown, disability remains an unmentionable topic and is frequently treated as if it is only to be found in actual damaged bodies (Marks, 2001; Watermeyer & Swartz, 2006).

The medical model took root in the nineteenth century as modern medicine began to develop, and arose alongside the increasingly prominent role that the physician played in society. Fully supported by ground-breaking advances in science and medicine, it gave the power and influence to the medical professions to dictate the lives of individuals with impairments. Such individuals were made the responsibility of the medical profession and were placed in the sick role. Sick people are excused from the normal obligations of society; they do not go to school, get a job or take on family responsibilities et cetera (Kaplan, 1999).

Thus, this medical approach sees disability as the outcome of impairment, separating disabled from non-disabled people purely on the grounds of biological

and psychological difference, and assuming a certain standard from which disabled people deviate (Barnes et al. 2002; Marks, 2001; Shakespeare, 1996). Disabled people are defined as those whose bodies malfunction, who look and act differently from others, and who cannot do productive work (Shakespeare, 1996).

Hughes (2002) observes that modernity and medicalisation are historically linked, producing a hegemonic conception of disability as an outcome of biophysical or mental impairment. Disabled people have broken bodies or faulty minds and as such have offended against a sense of order, representing a hint of chaos in a context dominated by clarity and perspective (Hughes, 2002).

Such an approach, according to Shakespeare (1996), could be considered essentialist and a form of biological determinism. Furthermore, in such an understanding of disability, where the focus is solely on the individual and his or her impairment, no questions are raised about the treatment or the definition of disability, nor is any interrogation of the positioning or treatment of disabled persons by society enabled. It comes as no surprise, therefore, that across the world, as the disability movement has gained momentum, such individualised understandings of disability have come under criticism and a new dispensation has emerged (Watermeyer & Swartz, 2006).

2.4.4 The social model of disability

As the disability movement steadily gained momentum, the traditional, medical view of disability has been increasingly challenged, particularly by disabled people themselves. Inspired by the spirit of their time, characterised by the political and social upheavals of the period, this process escalated during the 1960's and 1970's and disabled people began to organise collectively to protest against discrimination (Barnes et al., 2002).

Proponents of a new, social approach to disability argue that disability is not so much to be found in the individual and his/her impairment but instead, people are disabled by the social and environmental context (Marks, 2001). Consequently, the medical (and essentially modernist) understanding of disability has been contested and

transformed by a new political discourse in the form of the social model of disability (Barnes et al., 2002; Hughes, 2002; Marks, 2001, Shakespeare, 1996).

The social model generated in Britain during the 1960's and 70's, where disabled people were united by a shared experience of exclusion and prejudice (Barnes et al., 2002; Marks, 2001), attempts to neutralise the essentialism inherent in traditional approaches by showing that instead of disability being placed within the body (seen as the result of impairment), it should rather be understood as a form of social oppression or as a constructed category. That is, it is not primarily impairment that is viewed to exclude and oppress disabled people; rather, it is policies and environmental barriers that create and maintain the category of disability. Thus, people with impairments are mainly disabled by society's failure to accommodate their needs (Barnes et al., 2002; Marks, 2001; Shakespeare, 1996; Thomas, 2002).

To summarise, instead of seeing disability as the result of impairment, an individual problem, or a random tragedy, social model theorists argue that disability is created and maintained by a disablist society through the entrenchment of barriers to the participation of people with impairments (Watermeyer & Swartz, 2006). It sees many of the restrictions imposed on disabled people not as a natural or inevitable consequence of their impairment, but as a product of a social environment which fails to take account of certain people. For example, the absence of ramps can disable wheelchair users, the implication being that a person in a wheelchair is only disabled if the environment is not designed for people with wheelchairs (Marks, 2001). Accordingly, Barnes (1994, in Thomas, 2002) views disability as loss or limitation of opportunities, due to physical and social barriers, to participate in day-to-day community activities on an equal level with others.

Thomas (2002), in defining disability as a type of social oppression, rather optimistically holds that disablism has been ushered in alongside sexism, racism and other discriminatory practices as oppressive markers of differentness. However, despite the fact that an individualised understanding of disability has been challenged by a new political discourse in the form of the social model, and disablism is experienced by many as a form of social oppression, the concept of the broken body remains, for many people, firmly linked to impairment (Marks, 2001;

Watermeyer & Swartz, 2006). Disablism might well find itself in the company of sexism, racism and other discriminatory practices as an oppressive marker of differentness, but it is not yet a fully-fledged member of this society. The reality of the matter is that the term disability does not always bring to mind social oppression, systematic discrimination and disadvantage (Watermeyer & Swartz, 2006). Many people persist in thinking (inadvertently or not) of disability in terms of impairment only, as a personal tragedy, a problem located within the individual, something that certainly has nothing to do with society (Marks, 2001).

2.5 The embodied experience of disability

The social model in its pure form relies on a historical materialist view which focuses on tangible barriers to participation. In its early stages it had materialist undertones, which were the roots of the exclusion and social oppression due to various barriers, social, economic and environmental. These were experienced by disabled people and were sought in the social relations of the capitalist system of commodity production (Marks, 2001; Thomas, 2002). This is a social creationist position, in that it is the material nature of society that creates disadvantage (Watermeyer, 2013).

More recently, a difference of emphasis has taken place and social constructionism, which sees individuals as fundamentally enmeshed within social, cultural and historical processes (Nightingale & Cromby, 1999), has become an important theoretical framework for the social model of disability (Marks, 2001; Shakespeare, 1996). According to a constructionist view, the nature of society is a function of culture, focusing on the ways in which impairment is culturally represented and thought about, calling the very category of disability into question and in the process, leaving the body out of the picture (Watermeyer, 2013).

Social constructionism shares much of its theoretical basis with post-structuralism. Both question the whole concept of objective truth, distrusting the very notion of reason, and the idea of the human being as an independent entity, preferring the notion of the dissolved or constructed subject, whereby the individual is a product of social and linguistic forces (Barry, 1995). In an attempt to transform and reconstruct social constructionism, Nightingale and Cromby (1999) argue that social constructionism is too focused on language and discourse and should, in order to

explain the world in all its “extra-discursive intransigence and mess” (Nightingale & Cromby, 1999, p. 26), include other vital issues like embodiment. They feel that there is a need to challenge the dominance of relativism. The idea is not to universalise relativism, but rather to point out that there is in post-modern culture a largely uncritical acceptance of relativism, which, they contend, contributes substantially to and undermines any attempts to reincorporate the real, the extra-discursive (Nightingale & Cromby, 1999).

However, in terms of the social model view, the attention must remain on the real, material issue of barriers to participation and not on any exploration of personal aspects of disability. Also, as a result of the social constructionist character of much of the social modelist theorising, the body (the real) has unfortunately been removed from the definition of disability. With this, impairment has been conceptually severed from disability and the body has, in the process, been taken away from the experience of disability (Hughes, 2002).

Traditional approaches may thus have been questioned and transcended by the social model of disability, but this has constructed a new modernist dualism between the biological and the social, that is, between impairment and disability (Hughes, 2002; Shakespeare & Watson, 2002). Hughes (2002) argues that the analytical usefulness of this dualism is outmoded. According to Watermeyer (2013), the problem is not with the social model's emphasis on barriers and social responses to impairment, as those things are crucial. The problem is that the social model, in its pure form, is based on binaries. It relies on a split view of the world: the biological versus the social, impairment versus disability. He remarks that revolutionary politics in all forms relies on such splits and the disability movement is not alone in this. He concludes that it is now the time to have the courage to move towards a more nuanced politic, which is able to hold complexity (Watermeyer, 2013).

In response, proponents of the social model like Oliver (1996) and Barnes (1998), have argued that disability studies occupies itself with understanding and tackling the wider social causes of disability, rather than being particularly concerned with the personal experience of living with impairment. Any focus on impairment is regarded with suspicion, in that advances made by the social model's conceptual severing of

impairment from disability might be in jeopardy, lending weight to the 'impairment causes disability' position in the medical model of disability (Thomas, 2002).

However, arguments for the necessity of paying attention to the personal experience of impairment have come from many quarters. In particular, the failure of the social model to encompass personal experience within the concept of disability has been criticised by feminist disability writers (Crow, 1996; French, 1993a; Morris, 1991; Thomas, 2002). They argue that while environmental barriers and social attitudes do indeed disable and are a pivotal part of the experience of disability, the tendency within the social model to deny the experience of the body and to insist that physical differences and restrictions are entirely socially created, suggests that this is all that there is to the matter and is to deny the personal, real experience of living with a disability (Morris, 1991).

Thus, these authors argue for the return of the missing impaired body and for recognition of the role of impairment and personal experience in the lives of disabled people (Thomas, 2002). They say that, at the very least, "To leave out impairment means that it becomes difficult to distinguish disability from other forms of oppression" (Marks, 2001 p. 115) and at the very worst, no attention is given to the real suffering of disabled people in their everyday lives (Hughes, 2002).

However, when investigating the meaning of disability in terms of the real embodied experience (Hughes, 2002), such an exploration should not be viewed as an attempt to return the body to the centre as in the medical model. Rather, the idea is to focus on the real suffering of disabled people inclusive of personal experience, towards an innovative understanding of this multi-dimensional concept (Watermeyer, 2013).

2.5.1 The psycho-emotional dimensions of blindness

According to Thomas (2002), the psycho-emotional dimensions of blindness are those practices and experiences that affect the emotional and social well-being of blind people (Thomas, 2002). Thomas (2002) asserts further that although the social model does not deny the functional restrictions and physical experiences of impairment, these, however, do not constitute disability. She terms these limitations

impairment effects, thus bringing back into play the beleaguered disability-impairment distinction.

Reeve (2012) uses the term psycho-emotional disablism in this regard. She draws a distinction between structural disablism and psycho-emotional disablism. Structural disablism has an effect on activity, for example, when information is not provided in accessible formats or a wheelchair user is faced with a flight of steps. In such cases, the disabled person is prevented from doing something. In contrast, psycho-emotional disablism affects the sense of self, for example, being stared at or patronised by strangers. According to Reeve (2012), internalised oppression as well as disabling interactions with others are forms of psycho-emotional disablism.

According to Reeve (2012), psycho-emotional disablism is played out at the interpersonal level between disabled people and others. Non-disabled people's behaviour and attitudes might (inadvertently or not) disable. Negative attitudes towards disabled people are so prevalent in society that they can go unnoticed by non-disabled people and can influence attitudes towards disabled people and disability (Johnson, 2011). Reeve (2012) further holds that such psycho-emotional disablism is cumulative, and consequently, past experiences of being ridiculed or patronised, for example, may play out in current relationships. She highlights the possible damaging effects of psycho-emotional disablism on the self-esteem of a disabled person.

Reeve (2012) goes on to argue that the social model does not necessarily deny the existence of disabling barriers which operate at the psycho-emotional level but it is acknowledged in passing and then overlooked. Rather, the social model is generally used to identify and remove barriers which operate at the material, structural level, such as inaccessible transport and exclusion from employment and education (Reeve, 2012). However, the effect of this is that disabling barriers such as internalised oppression and disabling interactions with others are neglected.

In effect, the social model fails to include the body (and consequently also personal experience) within the concept of disability; these dimensions are excluded from the concept. In bringing back the missing impaired body, it has now become necessary

to pay some much needed attention to the body in relation to disability and to recognise the role of impairment and personal experience in the lives of disabled people (Watermeyer, 2013). According to Watermeyer (2013), the social model is incomplete without an account of the personal, as well as the psychological, but at the same time unable to accommodate one. The following statement by Jenny Morris relates to feminist discourse, but carries strong parallels:

Our anger is not about having a chip on the shoulder; our grief is not a failure to come to terms with our disability. Our dissatisfaction with our lives is not a personality defect but a sane response to the oppression which we experience. (Morris, 1992, p. 163)

Disabled people too have started to realise that their experience is noteworthy, and that the roots and consequences of oppression are to be found in both inner and outer circumstances (Hughes, 2002; Thomas, 2001). However, disabled life-worlds are riddled with psycho-political predicaments, cultural mechanisms which promote the turning inward of anger or distress, reducing social oppression to personal shortcoming (Watermeyer, 2013).

In not adopting an embodied and psychological construct of personhood, the social model seems out of step with contemporary shifts in social theory (Watermeyer, 2013). Social theorist Stephen Frosh remarks that “something unexpected” has taken place across social science disciplines, where the political has truly become personal – in fact, “some might say it has become so personal as to no longer be political” (Frosh, 1991, p. 1). Consequently it has been noted how prior paradigms unabashedly ignored the individual. As a result the self is to be investigated as a product and agent of social power (Honneth, 1995).

Further, traditional social theory’s fixation with material interest, with its consequent disregard for how the social order is shaped by moral feelings is criticised (Honneth, 1995). For Hoggett (1992) and others, a materialist orientation which denies the materiality of the body makes no sense, thereby dismissing the Marxist picture of humans as being a kind of putty which takes on the imprints of social forces (Hoggett, 1992, in Watermeyer, 2013).

Proponents of the social model, however, persist in clinging to the material, fearing that politics will so collapse into the personal as to no longer be political at all. Social model scholars regard any concern with personal experience or psychological explorations of disability as diversionary and pathologising; the cultural connection between impairment, pain, dysfunction and emotional suffering, confirming disability stereotypes of vulnerability, dependency and damage is to be avoided (Watermeyer, 2013).

Finkelstein (1996, p. 34) describes the concern with personal experience as a "discredited and sterile approach to understanding and changing the world", arguing that the disability movement has been hijacked by academics bent on replacing the active vision of resistance with "passive theoretical abstractions". Except for the work of Thomas (1999) and Reeve (2002), that augmented the social model, the essence of a steadfast materialist position remains upheld amongst members of the social model (Watermeyer, 2013).

However, while the field of disability studies was abandoning the concept of the body, the body was set to become a central site of engagement in other arenas of social struggle (Hughes & Paterson, 1997). Hancock and co-workers describe the scene as follows:

Meanwhile the body was making itself ever-present in social and political life, be it in the shape of a battered woman, a terminated foetus, a victim of torture or televised war, a proud celebration of womanhood, disability, colour or homosexuality, an organ in transit for transplantation, a human-machine stepping on the moon, a sample of DNA under the microscope, a man who was a woman or vice versa, a body transformed by diet, exercise or the surgeon's knife, a homeless person camped on the streets of the world's richest nation, a mass grave, another world record smashed.

But for disabled people relying on the social model account, the living, breathing body had vanished; in its place a timeless ontological foundation. (Watermeyer, 2013, p. 45)

Hughes and Paterson, in a critique of materialist disability studies, further describe the social model's construction of the impaired body as a "dysfunctional, anatomical, corporeal mass obdurate in its resistance to signification and phenomenologically dead, without intentionality or agency" (Hughes & Paterson, 1997, p. 327).

Social constructionism and the postmodern tradition offer an alternative strategy for making sense of what disability is. Constructionist disability theorists aim to remove "disability meanings" from a positivist theoretical framework, characterised as holding a "western conception of objective, individualistic, ahistoric knowledge" (Gergen, 1985, p. 272). This is a notable theoretical alternative to medical essentialism, but the disadvantage of this approach is that it cannot be articulated in concrete terms. Consequently, a strictly constructionist view of disability allows the body to be temporarily retrieved from an absolutised biological perspective, reinstating it as a frame for discursive struggle (Watermeyer, 2013).

No sooner has the body been secured as a contested space, however, than it is confronted with a new challenge: postmodern deconstruction, in terms of which all theoretically required delineations seem elusive and indeterminate, drained of all absolute categories of thinking (Price & Shildrick, 1998; Turner, 2001). As already noted, the social model accedes to the body by overlooking it, allowing no space for the experience of the disabled body.

However, the constructionist position fails to set matters on an equal footing (Hacking, 1999), replacing a bleak biological essentialism with an equally depersonalising "discursive essentialism" (Hughes & Paterson, 1997, p. 333). Instead of animating the body, deconstruction reduces it to nothing more than its constituent cultural signifiers (Watermeyer, 2013), whereas impairment is a complex, embodied process comprising both societal and personal aspects. In exploring the embodied or real experience of disability, accounts of personal experience inclusive of experiences of loss and suffering as well as the role and impact of others' responses to blindness must be included.

The following broad observations are submitted in order to provide a context within which the psycho-emotional dimensions of blindness operate in the lives of blind

people. Like other disabled people, most blind people live their lives amidst a world of disablism. They may find themselves frequently defined by hidden assumptions, stereotyping and sometimes outright prejudice. The implication of this is that disabled people including blind people may experience being viewed and treated as not whole, not normal, capable of nothing, totally dependent, unable to do anything for themselves or for others, and as if they are alien and do not belong (Marks, 2001; Morris, 1991; Watermeyer, 2006).

Moreover, more often than not, disabled people may find that they are not viewed or treated as ordinary people going about the ordinary business of life inclusive of all its ups and downs. Instead, they are frequently perceived as either pathetic, tragic figures or super-heroes (Marks, 2001; Watermeyer, 2006). Therefore, living as they do, in an often inaccessible and inequitable world of disablist exclusions, whilst at the same time being treated in terms of incorrect assumptions as well as encountering attitudes imbued with psychic investments, it comes as no surprise that the psychological and emotional well-being of some blind people may have been negatively influenced (Marks, 2001; Reeve, 2012; Watermeyer, 2009).

2.5.1.1 Hidden assumptions and stereotyping

It is argued here that much of the interaction between the blind and the sighted world is largely informed by hidden assumptions (Morris, 1991). These assumptions are referred to as hidden because they are often implicit and only partially conscious; that is, sighted people are for the most not aware of them. Being hidden and largely unconscious, these assumptions are evident only via the behaviour of the sighted person, in how such a person responds to and treats blind people (Morris, 1991; Watermeyer, 2009).

When a sighted person encounters a blind stranger, the sighted person may experience anxiety, apprehension, uncertainty and other deeper, darker unconscious feelings evoked by the other's blindness (Marks, 2001; Watermeyer, 2006). The consequent response is informed by hidden assumptions concerning blindness and blind people. As the sighted person has no knowledge of such a blind stranger's life experiences, internal world, sense of self, abilities, shortcomings, hopes and fears, any assumptions and associations that the sighted person may harbour can only

have originated within the sighted person and is not logically a reflection of the real situation (Watermeyer, 2006).

Such hidden assumptions are largely informed by certain societal discourses regarding blindness and blind people, and they shape the way blindness is understood and treated. Chief of these discourses is the medical model, a model that links disability exclusively with impairment and views it as a random tragedy and entirely a personal problem (Marks, 2001). Consequently, blind people are linked with ideas of tragedy, dependency, helplessness, pity, loss and suffering, and so on.

As interactions with blind people are frequently based on such hidden and usually incorrect assumptions (Morris, 1991), this may have a negative impact on the emotional and social well-being of some blind people. Such blind people may internalise such undermining responses from the sighted world; such assumptions may become part of the way that blind people think and feel about themselves (Marks, 2001; Morris, 1991; Reeve, 2012). Some of these assumptions include: that blind people are unable to do things for themselves or for others, that they cannot hear, speak or think for themselves, that they are linked to certain jobs only, and that they always need help (McDougall, 2006; Morris, 1991; Watermeyer, 2006).

Responses to blind people may also include stereotypical thinking. Rowland (1985) holds that stereotyping is a way in which one group views another by consciously or unconsciously selecting a limited number of characteristics and attributing them to the other group as if they were typical of it. He notes that such stereotyping may be positive or negative: "What blind person is there who cannot call to mind some incident in which an uninformed stranger treated him as though he were helpless and pitiable, or, on the positive side, as if he were in possession of some remarkable faculty, say, of hearing or touch?" (Rowland, 1985, p. 1).

One frequently evoked stereotype is that disabled people, including blind people, are pathetic and dependent. They are perceived as the innocent, poor and tragic victim in need of assistance, thus reducing their identity to the single distortion of dependency. They are viewed as unfortunate and disadvantaged, only to be pitied (Clogston, 1990, in McDougall, 2006).

On the other hand, a response to this negative portrayal of disability as being synonymous with dependency and pity is to insist on representing the positive, that is, in some or other way, portraying disability as heroic, the super-crip (Shakespeare, 1996). But, instituting a complete reversal does not necessarily mean the production of accurate and empowering portrayals of disability (McDougall, 2006).

In the first place, the truth of the matter is that the popular belief that the blind person is compensated for a loss of sight by the greater acuteness of his/her other senses is contrary to fact. Carroll (1961) says that empirical data suggest poorer sensory performance in general among blind people. He draws a distinction between sense acuteness and sense efficiency. Where blind people show heightened efficiency, Carroll (1961) says it is because of their greater concentration, or the result of training and experience.

Being inaccurately described as remarkable or heroic can thus be demeaning to blind and other disabled people. For example, people frequently make comments to disabled people (often disabled people with whom they are scarcely acquainted) such as: 'You are a special person', or 'I think you're really brave', or 'I think you are really courageous just for being who you are'. However, as the disabled person is often a stranger to them, this kind of comment is not based on who the disabled person is, or what he/she has accomplished, but rather on the basis of stereotypical thinking or the sighted person's own assumptions about disability. Remarks such as, 'I take my hat off to you' and 'I don't know how you do it', far from being the antidote to pity, more often arouse it (McDougall, 2006).

In attempting to explain why the blind person is sometimes portrayed as heroic and unusually and somewhat unrealistically capable, Watermeyer (2006) provides some insights based on psychoanalytic theory. He observes that this may reflect a need within the sighted person to overcome the fear that the blind person is totally restricted and capable of nothing. The sighted person, who has feelings of deep inadequacy evoked in response to the idea of living with blindness, manages such feelings by a form of reversal. This then makes it necessary to portray the blind person as heroic. Presenting the blind person in such a way permits the sighted

person to feel reassured that the blind person's life is not the unmitigated tragedy which they fear and 'know' it to be (Watermeyer, 2006).

Furthermore, according to Rowland (1985), these stereotypes may be applied with such conviction that they even have persuasive force in influencing the way in which the group, so viewed, perceives itself. Thus, such stereotypes, as well as other negative responses, may become part of how some blind people think of and see themselves. In this way, the stereotypes are internalised by blind people, which may lead to internalised oppression (Marks, 2001; Rowland, 1985). The identities 'piteous', 'dependent', 'unfortunate', 'disadvantaged', and 'not normal' may become part of how some blind people see themselves. This may result in feelings of inadequacy, self-doubt, worthlessness and inferiority (Barnes, Mercer & Shakespeare, 1999).

Some blind people may therefore manage by capitulating to imputed assumptions and stereotypes; they 'become' the disabled characterised in the stereotyping via internalised oppression, experiencing themselves as nothing more or less than what the stereotypes dictate (Morris, 1991; Watermeyer, 2009). On the other hand, many disabled people, including blind people, devote their lives to the disproving of imputed negative associations and assumptions. As a form of resistance, they define themselves in opposition to negative imputations by overturning such expectations and ensuring that there is nothing in their behaviour to draw the attribution of such traits (Watermeyer, 2009).

2.5.1.2 Psychic investments

Before commencing this section, it should be noted again that throughout this study, the literature, as well as the data, are interpreted through a particular lens, that is, to investigate the real experience of living with blindness amidst a disablist world in terms of the particular research agenda. This includes an exploration of others' attitudes in terms of psycho-emotional disablism, hidden assumptions and psychic investments. This, however, in no way implies that there are not also positive attitudes toward the disabled. Indeed, positive qualities and virtues are often exhibited in the context of interaction with the disabled. These may include compassion, courage and empathy. However, these are not the focus of this

particular study. Furthermore, what follows below with regard to psychic investments is not intended to suggest that sighted people consciously respond to blind people in the ways highlighted here. The functioning of the defence mechanisms discussed below operate exclusively on an unconscious level.

By means of introducing the workings of psychic investments in the context of interaction with the disabled, Marks (2001) comments that there is often an uncomfortable silence around disability and disabled people which affects the way such people are viewed and consequently treated (Marks, 2001). By way of explaining this uncomfortable silence, some insights of psychoanalysis are utilised. Thus, it is argued that non-disabled people's attitudes to disability are imbued with psychic investments, in the form of a psychic payoff (painful or unpleasant aspects of self have been linked to and then projected onto disabled people and thus disowned) (Marks, 2001).

In justifying the use of insights from psychoanalysis, Watermeyer (2013) contends that relationships between disabled people and others are unequal, and largely informed by hidden meanings about what disability is, what it does and what ought to be done about it. Consequently, much of what maintains inequality in disabled lives remains on an unconscious level, leading to responses or feelings which are difficult to understand (Watermeyer, 2013). He adds that insights from psychoanalysis have the potential to make sense of not only inter- and intra-personal relationships, but also of the wider hidden meanings of disability associated with, for example, policies, assistive devices, social service protocols and architecture. A critical psychoanalytical view, therefore, does not necessarily only focus on the nature of the personal experience of disability, but is also concerned with disability meanings held by all, disabled and non-disabled alike (Watermeyer, 2013).

By means of introduction to the nature and operation of psychic investments, Marks (2001) explains that we find ourselves amidst a narcissistic culture in which people strive for perfection and independence; thus, the parts of the self which are unacceptable (such as bodily imperfection and dependency) need to be kept outside conscious awareness. Consequently, these are split off and projected onto disabled

people (in this case blind people), that is those who have been socially constituted as damaged (Marks, 2001).

Using some of the insights of psychoanalysis, Watermeyer (2006) further explains that Freud's model of the psyche consists of a conscious as well as an unconscious part. Troublesome ideas, which are difficult to accept in conscious awareness, are repressed into the unconscious and kept in place by defence mechanisms (Marks, 2001). These troublesome, unwanted parts of ourselves (for example, of being unlovable, of not being capable or adequate, of vulnerability, dependency, shame and fears that we are unacceptable to others, or that we are a burden to others) become attached to ideas and images of disabled people (Watermeyer, 2006).

As a result, disabled people come to symbolise what is damaged, undesirable, shameful and unwanted, parts of being human which all of us carry within ourselves, but are reluctant or unable to own (Marks, 2001; Murphy, 1990; Shakespeare, 1994; Watermeyer, 2006). Consequently, when encountering disability, we experience our own difficult, troublesome or painful parts as if they do not belong to us but to the disabled person, the other, allowing us the excuse of believing (consciously) that it is the other who is the owner, the caretaker of what belongs to us, and what we would rather disown (Oliver, 1990). Thus, people habitually repress certain existential anxieties and disability, and disabled people have come to represent these feelings. In effect one might say that non-disabled people treat disabled people as "dustbins for disavowal" (Shakespeare, 1994, p. 283).

In terms of this model, the conscious mind manages the threat of such painful or difficult feelings intruding from the unconscious, by means of the deployment of defence mechanisms (Marks, 2001; Watermeyer, 2006). The following are some of the defence mechanisms specifically applicable to others' attitudes to disability and to psychic investments: projection, reaction formation, splitting and idealisation. These will be discussed in some detail below.

The defence of projection

As discussed above, encountering a blind person evokes feelings which a sighted person cannot endure in him- or herself. In terms of this defence, the sighted person

then reconstructs the blind person as the owner or caretaker of such feelings. Marks (2001) regards projection as the key tool for understanding the psychic mechanisms of prejudice against disabled people. The blind person is experienced as being in possession of some of the sighted observer's internal feelings. Unthinkingly, and for unconscious reasons, the blind person is made into the vulnerable, admirable, wretched, courageous, tragic, damaged, isolated, unable or virtuous person that the mind of the sighted person, for his/her own unconscious reasons, requires such a blind person to be. In the gaze of the sighted observer, the blind person becomes the other, an object on whom to confer the sighted person's 'unwanted' internal feelings (Marks, 2001).

The defence of reaction formation

This defence operates when sighted people want to avoid acknowledging unacceptable feelings and impulses evoked by blindness; therefore, the sighted feel pity and may for example, offer help. According to Marks (2001), expressions of pity and offers of assistance might in fact function to disavow unconscious sadism (Marks, 2001). Such offers of assistance are explained by Braverman (1951) as follows: contact with the blind person triggers a whole train of emotions in the sighted. Blindness evokes the castration fear which gives rise to a feeling of revulsion towards the blind. The impulse accompanying this feeling of revulsion is that of wanting to banish from sight the object causing the reaction. Since such a desire is unacceptable in our society, the sighted experience guilt accompanied by anxiety. The cause of this anxiety needs to be hidden and the sighted person seeks to free him- or herself of it by turning the initial feeling of revulsion into the acceptable feeling of pity.

This results in help being given that satisfies the giver rather than the receiver. According to Braverman (1951), pity is degrading to the blind person because it implies his/her inferiority, a position made worse by the blind person being expected to display gratitude. Failure to do so arouses fury because the sighted person's anxiety cannot be allayed until his/her pity receives expression and recognition. Braverman (1951) contrasts kindness with pity. Kindness, she claims, is almost the exact opposite of pity in that it is a response to the real situation.

Watermeyer (2006) explains the common urge to offer assistance, in terms of the fact that meeting with a blind stranger is threaded with anxiety. This anxiety in the sighted person may, sometimes, consciously be managed by taking control and providing uninvited assistance. However, on an unconscious level, if the sighted person does not know how to interact with the blind person, the sighted person must be acting on an assumption concerning the blind person and his/her life; for example, that the blind person is unable to do anything for him/herself, or that the blind person needs assistance. This common urge to offer assistance is thus based not on the real situation but rather on assumptions regarding the needs, capabilities and vulnerabilities of such a blind person (Watermeyer, 2006).

The defence of splitting

This defence takes the form of black-and-white categorical thinking which tends to bias thinking towards a belief that the world can be divided clearly into a set of binary opposites, such as normal or abnormal, or able or unable. This thinking assumes that there exists a clear boundary between these opposing categories and that consequently there are no grey areas, leading to individuals being attributed with all good or all bad qualities (Marks, 2001; Watermeyer, 2006).

The illusion that people can be categorised as either disabled or not disabled reflects a form of split thinking (Watermeyer, 2006). Again returning to a meeting of the sighted person and a blind stranger, the sighted person categorises what he/she sees in this way. In this situation, upon being confronted with another's blindness, he/she feels anxious, and consequently needs to establish a sense of control. Coping in terms of this defence implies that, in the face of threatening fears about what a blind person's life may be, the sighted person achieves a sense of mastery and control by deciding that the blind person's life is actually the way it is fearfully imagined to be. Furthermore, it often feels more manageable for the sighted person to view a blind person as necessarily damaged and vulnerable, than to feel the prompting of these very feelings within themselves, and to be unsure whether or not they apply (Watermeyer, 2006).

The defence of idealisation

The defence of idealisation involves the attribution of excessive, unreal, overly positive characteristics to blind people and is usually employed together with split thinking. Watermeyer (2006) observes that this may reflect a need within the sighted person to overcome the fear that the blind person is totally restricted and capable of nothing. The sighted person who has feelings of deep inadequacy and incapability evoked in response to the idea of living with blindness, manages these feelings by a form of reversal, which makes it necessary to portray the blind person as heroic and unusually and somewhat unrealistically capable. The blind person has been presented in such a way as to permit the sighted person to feel reassured that the blind person's life is not the unmitigated tragedy which one fears, and 'knows' it to be (Watermeyer, 2006).

Together with the aforementioned defence mechanisms on the part of the sighted with respect to the phenomenon of blindness and blind people, the attendant experience of actually living with blindness warrants investigation. Like other disabled people, most blind people live their lives not only amidst a world of disablism, but may experience at the same time being viewed and treated in terms of others' mostly incorrect assumptions. They may also regularly encounter attitudes imbued with psychic investments. Taking all these aspects into account, it is understandable that the psychological and emotional well-being of some blind people may have been negatively influenced (Marks, 2001; Watermeyer, 2009). In exploring the embodied or real experience of disability, accounts of personal experience inclusive of the impact of others' responses to blindness as well as possible loss and suffering related to living with blindness must be included.

2.5.1.3 Living with impairment: The loss discourse

An exploration of the real experience of disability, that is, of the personal experience of living with impairment should include an investigation of the impact of living with impairment on the emotional and social well-being of blind people, inclusive of accounts of experiences of loss and suffering (Crow, 1996; French, 1993a; Morris, 1991; Thomas, 2002).

Along with feminist disability writers (Crow, 1996; French, 1993a; Morris, 1991; Thomas, 2002), it is argued that there is no doubt that environmental and social barriers disable and as such form an essential part of the experience of disability. However, the social model's denial of the experience of the body amounts to a denial of the personal real experience of living with a disability (Morris, 1991). As a result of this, recognition of the role of impairment and personal experience in the lives of disabled people is overdue and needs to be acknowledged, but in such a way as not to lend weight to the 'impairment causes disability' position of the medical model (Thomas, 2002).

Acknowledging the role of impairment in the lives of disabled people implies an exploration of experiences of loss and suffering. Addressing the experience of loss in particular is problematic. Within medical and rehabilitation approaches on the one hand, the idea of disablement is associated with suffering and the experience of loss. Consequently, disabled people are linked to loss and suffering and are as a result expected to feel a sense of loss.

Yet, on the other hand, they are often at the same time socially forbidden from articulating this (Watermeyer & Swartz, 2008, in Watermeyer, 2009). Many disabled people do not allow themselves to enact any impairment-related behaviour within the social arena for fear of being defined solely in terms of such behaviour; instead, they are silent about substantial areas of experience. Therefore, they find themselves living in spaces of marginalisation and alienation (Watermeyer, 2009).

However, by the sheer virtue of being human, everyone experiences loss and suffering, and all should be able to articulate this. In order to facilitate a sense of being whole, of being authentic, everyone, including disabled people, needs to be heard, to be understood and to be known by others. It is hard to cultivate self-acceptance and integration of one's difficult and painful experiences if one is not granted the opportunity to reveal, examine and share these with others (Watermeyer, 2009).

It therefore makes no sense to attempt to dissociate blind people from the experience of loss and personal suffering. Disabled people, however, are not free to

safely articulate loss, because they are perceived as having suffered irrecoverable loss, a loss that is seen as part and parcel of such a disabled person, with the disabled person becoming the very personification of loss (Marks, 2001; Shakespeare 1994).

The challenge is to find a way for disabled people to own up to loss without having to be defined in terms of loss. The problem is that although the experience of living with impairment amidst a disablist world with internal and external silencing forces operating is clearly real, it has largely remained uninterrogated and unexplored (Watermeyer, 2009; 2013). This is because any focus on impairment, loss or personal suffering is regarded with grave suspicion, especially by social modelists, who fear that progress made by the social model's conceptual severing of impairment from disability might be in danger of being undermined. This would give succour to individualising medical constructions of the concept of disability (Thomas, 2002).

In this regard, Watermeyer (2009) remarks that within medical and rehabilitation approaches the idea of disablement is associated with suffering and the experience of loss. Also, there is a long history of using grief and bereavement models to construct disability as a loss that must be adjusted to or overcome. Accordingly any attempt to include the experience of personal suffering within the concept of disability is strongly rejected in particular by social modelists, as a form of stereotyping which perpetuates views of disabled people as incomplete, vulnerable or needing rehabilitation (Abberley, 1993; Finkelstein & French, 1993; Morris, 1989; Oliver, 1990).

Watermeyer (2009) further argues that to be human implies the suffering of loss, whether one is disabled or not. Therefore, the problem is not the experience of loss per se, but rather the way in which the idea of loss is distorted and perverted in the lives of disabled people. He says that what is specifically at issue here is not the real losses that disabled people suffer in the course of their everyday lives, but rather the fact that disabled people have been selected out from the rest of humanity to receive others' projected feelings of loss (Watermeyer, 2009).

This kind of loss is understandably experienced as an affront by the disabled community because such loss does not belong to disabled people, but exists essentially in the minds and classifications of others and mainly for their benefit, in the form of psychic payoff (Marks, 2001). Aspects of real loss have been linked to, and then projected onto, disabled people and thus disowned. Being positioned as having to deny imputed loss may place disabled people at risk of suffering self-alienation relating to a way of being which is preoccupied with not being the personification of stereotype at the expense of aspects of identity and self (Watermeyer, 2009).

Moreover, any disability conversations which do take place may be more for the reassurance of the observer than to offer an opportunity for the disabled person to be heard or understood. French (1993c) explains that when encountering disability, anxiety is produced within the observer which often leads to defensive manoeuvres, including intervention.

For the disabled person, on the other hand, the particular disability experience is an everyday occurrence which does not require intervention, but is worth consideration or communication for personal and not for practical reasons. Thus, the experience itself remains unheard, unintegrated, disguised by the disabled person's assurances that it is manageable and an ordinary everyday experience, the reassurances serving only to manage the anxiety of the observer (French, 1993c; Watermeyer, 2009).

Disabled people manage in various ways; for many disabled people, the disproving of negative imputations is more important than any exploration and expression of aspects of the self. Such disabled people may therefore define themselves in opposition to negative imputations. Living in a world of disablist exclusions, it is not always possible for disabled people to avoid all behaviour which may evoke stereotypes. This, according to Watermeyer (2009), in essence, is a form of oppression in which disabled people, in contesting demeaning stereotyping, are precluded from being allowed to show or communicate universal aspects of human emotional life (Watermeyer, 2009). Yet other disabled people manage by becoming

the stereotype. Seeking an identity centred in personal suffering may serve to validate such disabled people (Marks, 2001; Morris, 1991; Watermeyer, 2009).

Some disabled people disassociate themselves completely from loss. Empirical studies have produced evidence that many disabled people do not identify the onset of, or a life with disability, as loss (Campling, 1981; Morris, 1989; Finkelstein & French, 1993). For these people, disability is viewed as an enriching life experience, one which may lead them to ask questions about assumptions regarding the human condition and the workings of society. The argument is that disabled people ought to be allowed a silent space of non-judgmental solidarity where they are able to voice personal experiences of disability without falling prey to the tyranny of hidden assumptions and stereotyping, ultimately with their experience possibly contributing to the creation of a more human, caring and critical world (Davis, 2002; Michalko, 2002).

Watermeyer (2009) notes that these latter accounts of disability seems to imply the eschewing of loss and struggle in the lives of disabled people. This is a reactionary emphasising of the positive in response to the damning negative. He contends that reacting by disclaiming loss in any form must also be seen as a form of dehumanisation. In order to overcome or disprove a prejudice, one is compelled to define oneself in opposition; this involves subjectifying oneself to the prejudice as fully as if one had allowed oneself to confirm it.

On the other hand, Watermeyer (2009) observes that phenomenological or experiential accounts of disability inclusive of accounts of personal suffering and loss can be criticised as supportive of medical, charity and dependency discourses. These narratives in their turn may stand accused of having emphasised the damning negative (Watermeyer, 2009). Rather than focusing on either, Watermeyer (2009) comes to the conclusion that what is actually required is that the very foundation common to both must be subverted and reconceptualised (Watermeyer, 2009). There must be a way negotiated for disabled people to live their lives authentically; that is, they ought to be able to articulate having suffered loss without having themselves defined in terms of such loss.

In the struggle for an autonomous and audible voice, loss must be reclaimed and the enforced attachment or dissociation of loss from disability needs to be rejected. Instead, disabled people must, in reclaiming and welcoming back loss and other painful aspects of their existence, like all people, make these their own, part of themselves and of their own subjective life (Watermeyer, 2009).

However, for disabled people, it requires courage to describe the experience of loss. In disclosing and showing difficult, even shameful parts, disabled people need to know that it will not contaminate their identity in the view of the listener, that they will remain the same to the other (Watermeyer, 2009). Watermeyer (2009) remarks that these are of course, challenges faced by all, but for disabled people the risks are higher. It is not only what the disabled individual relates that impacts on his/her social identity, but also the ever-present undertones of loss-related stereotypes in the social world, which are so easily ignited by any conversation on loss. In the mind of the other, at both a conscious and unconscious level, there are certain fantasies of loss and struggle concerning the experience of being disabled that are often just waiting to be confirmed.

As a result, an image of the disabled person as the very personification of loss is never far from the surface and often slots unsolicited into place. Disabled people may consequently be left to bear attributions of losses which are not theirs, whilst at the same time live in a space where they are also not being allowed to show or communicate experiences of loss that are theirs by virtue of being human (Watermeyer, 2009).

2.6 The experience of the body: Accounts of loss and personal suffering in living with impairment amidst a disablist society

As argued previously, it is clear that there is almost universal recognition of disability as a social issue. Thus, consideration of the social and economic context within which people experience impairment is well-established and a crucial component of disability (Morris, 1991). However, in the process, a whole area of human complexity has unfortunately been silenced (Watermeyer, 2013). It is argued here that any exploration of the experience of disability which persists in maintaining that physical differences and restrictions are entirely socially created is simply no longer tenable

as this tries to deny the role of the body (Morris, 1991). The 'real experience' needs to be recognised and included in order to have a full understanding of the concept and also the experience of disability.

The use of the term 'real experience of disability' (the actual experience of living with impairment amidst a disabling world), however, does not imply an exclusively essentialist view which is in tension with an understanding of disability as socially constructed. The argument is that social constructionism, which serves as a theoretical framework for the social model, overemphasises language and discourse; thus disability is seen as a constructed category (Hughes, 2002; Shakespeare, 1996) and as a consequence the body is not part of the definition or experience of disability. Therefore, in order to explain the world, the real, the extra-discursive, must be reincorporated; vital issues like embodiment should be included (Nightingale & Cromby, 1999). Embodiment is what survives of essentialism after the challenge of constructionism.

Further, it must be emphasised that attempts to incorporate the experience of the body (inclusive of accounts of loss and other painful aspects of living with impairment) into the concept of disability, in no way suggest a return to an individualising, medical interpretation of disability. Instead, the idea is to give some much needed recognition to the real suffering of disabled people (Hughes, 2002).

In the following section, some losses associated with living with blindness are discussed. The intention is not to ascribe all the losses to all blind people or in fact to any of the participants. Neither is it to suggest that living with blindness necessarily implies any particular loss, nor that all loss is due to impairment. Some of the losses of living with blindness are entirely the result of social factors.

As a result of the social model holding academic sway since the late sixties, it has been challenging to access any current literature on the experience of loss related to blindness. The researcher therefore has made use of the work of Carroll (1961), who worked extensively with the rehabilitation of blind people. The intention with this, however, is not to view disability through a pathologising, individualising lens, but rather to utilise Carroll's work to form a framework for the discussion that follows.

Before commencing this section, it is worth noting that the intention of this study was not to draw any comparison between those who are congenitally blind and people who have lost their sight later in life. However, regarding certain of the losses mentioned below, the experience of loss may differ according to when a person has lost his/her sight.

Carroll (1961) has identified some of the possible areas of loss that may relate to living with blindness. However, he observes that these areas might in fact not be the only experience of loss, as in his opinion, blindness has the power to affect the whole person and may result in a multiplicity of losses. Furthermore, according to Carroll (1961), the impact of such an experience of loss may lead to various reactions to blindness including anxiety, denial, resentment, hostility, and many others.

2.6.1 Self-worth and self-esteem

Carroll (1961) observes that every area of loss in a blind person's life, in some way or another, may affect such a person's sense of self and might consequently influence his/her self-worth. The areas of loss mentioned in this sub-section though, specifically impact on self-worth and self-esteem.

Broadly speaking, self-concept is the basic perception or knowledge that a person has of him- or herself. Self-esteem on the other hand, is a person's general attitude towards him- or herself (Pastorino & Doyle-Portillo, 2013).

Carroll (1961) refers to objective and subjective self-esteem in relation to blindness and asserts that loss of self-esteem takes place in terms of these two aspects. Loss in objective self-esteem is an intellectual devaluation which gradually takes place as the blind person discovers that in one area after another, he/she is disabled by his/her blindness. Subjective self-esteem, which reflects the thoughts and feelings the person has about him- or herself since childhood, is consequently constantly placed under a burden. The attitudes and actions of others also play a decisive role in this respect.

According to Marks (2001), the concept of internalised oppression is helpful here. Others' assumptions and negative responses concerning blindness and blind people may be internalised and as such may have become part of who blind people become and how they see themselves (Marks, 2001; Reeve, 2012). Marks (2001, p. 27) cites Mason (1992) who outlines the term as follows:

Internalised oppression is not the cause of our mistreatment; it is the result of our mistreatment. It would not exist without the real external oppression that forms the social climate in which we exist. Once oppression has been internalised, little force is needed to keep us submissive. We harbour inside ourselves the pain and the memories, the fears and the confusions, the negative self-images and the low expectations, turning them into weapons with which to re-injure ourselves, every day of our lives.

According to Marks (2001), blind people may consciously or more likely unconsciously internalise exclusion, marginalisation and rejection. This may lead to psychological responses like compliance, resistance, anger, withdrawal and despair. As this happens mostly on an unconscious level, we are unaware of it. Some experiences may be so painful that they are repressed from conscious awareness. Yet they continue to affect self-esteem and shape thoughts and actions (Marks, 2001).

2.6.1.1 Loss of physical integrity

Body image is an important part of a person's self-concept. Being suddenly blinded or living with blindness over a long period may deal a devastating blow to body image and may result in a loss of physical integrity, a loss of wholeness, even to insecurity about one's very humanness. Consequently, feelings of not being physically competent, able, adequate or attractive may arise. Moreover, feelings of being different from other people, of not being normal, and even of exclusion from the group may also be present (Carroll, 1961).

Watermeyer (2006) remarks that it is not only non-disabled people who might, as a result of unconscious investments, respond irrationally to disability. Often blind people find their own difference problematic; they may feel for themselves rejection, pity, and even revulsion. They too have connected ideas and images of disabled

people to unwanted parts of themselves. And like everyone else, their conscious minds manage the threat of painful or difficult feelings encroaching from the unconscious, by means of the deployment of defence mechanisms (Marks, 2001; Watermeyer, 2006).

Regarding disabled people's perception of their bodies, it has been suggested that somatic knowing contributes to the way that humans perceive and conceive of the world (Merriam, Caffarella, & Baumgartner, 2007). Although the concept of embodied cognition in the context of disabled adult learners does not fall within the ambit of the present study, the work of Rule and Modipa (2012) has been included in as far as it relates to the 'broken body' and others' attitudes to disability. In an article exploring the attitudes and experiences of adults with disabilities regarding education, where the role of the body in adult learning is considered, Rule and Modipa (2012) investigated the role of embodied cognition in shaping knowing. Embodied cognition sees bodily situatedness as central to the way humans perceive and conceive of the world. It is argued that the way people are embodied affect the way they know the world (Rule & Modipa, 2012).

Rule and Modipa (2012) employed Gallagher's (2005) notion of body image to understand adult learners' attitudes toward and experiences of education. For Gallagher, body image consists of three elements:

- body percept (the subject's perceptual experience of his or her own body)
- body concept (the subject's conceptual understanding, including folk and/or scientific knowledge of the body in general)
- body affect (the subject's emotional attitude toward his or her body).

Rule and Modipa (2012) argued that this approach takes into account the centrality of the body to meaning-making and knowledge creation in a way that acknowledges perceptions, thoughts, and feelings holistically in relation to the environment. Their study found that impairment is linked directly to social discrimination, and that this shaped the body percepts, body concepts, and body affects of some of the interviewees. Further, some respondents reported incidents in which they were

recipients of the words and actions of others: they were acted upon, against, or on behalf of; they were insulted, or ignored. In all these cases they were silent.

According to the study, the data excerpts in the article underline the notion that embodied cognition is also social cognition. Through processes of discrimination, oppression, and silencing, society reproduces stigma inside the person as a form of internalised oppression, an imposed sense of one's own bodily deficit, which effects a particular negative body image. Thus, it can be argued that somatic knowing, in acknowledging perceptions, thoughts, and feelings holistically in relation to the social environment, contributes to the ways that adult disabled learners made meaning of their lives (Merriam et al., 2007). By way of analogy, this may apply to other areas in the lives of disabled people.

2.6.1.2 Social interaction

Many blind people experience social difficulties, not only because of blindness per se, but rather because of the way blindness and blind people are viewed and treated by the sighted world. Prolonged negative social interaction with the sighted world may lead to the blind person experiencing a loss of social adequacy. According to Carroll (1961), the loss of social adequacy may well be perceived by blind people as one of the most severe losses amongst the many losses constituting the personal experience of living with blindness.

He holds that this loss is twofold; firstly, due to, for example, the inability to make eye-contact, the blind person may experience difficulty interacting with others, resulting in such a blind person developing negative feelings regarding social interaction. Secondly, others also contribute largely to this loss because of their discomfort around blindness and blind people (Carroll, 1961; Marks, 2001).

Marks (2001) explains this discomfort in terms of the psychoanalytical model. The blind person is reconstructed as the caretaker of feelings which the sighted person cannot endure in him- or herself. This may result in the sighted person simply looking the other way avoiding the blind person. Alternatively, feelings of revulsion may be hidden with reactions of pity and the urge to offer unwanted assistance may arise (Marks, 2001; Watermeyer, 2006).

Furthermore, the way blind people think and feel about themselves may be affected by the very experience of sighted people's reactions to physical difference (blindness). Such a blind person may become aware that he/she is someone whose physical condition others dread or fear. When told by both strangers and acquaintances alike, how wonderful they think the blind person is, instead of experiencing this as affirmation, it may provoke feelings of hurt or anger. This is so because on a rational level, the blind person is praised for struggling against the difficulties which physical disability brings, but on a much deeper unconscious level lies the judgement that being disabled must be awful, indeed intolerable. It is very undermining for the blind person to recognise that others look at him/her and see an existence, an experience which they dread or would do everything to avoid for themselves (Morris, 1991).

A further problem inherent in interaction between the blind and the sighted world is that hidden assumptions underpin most of such interactions (Morris, 1991). Also, like other disabled people, the blind are subject to stereotyping in various ways (Rowland, 1985). The effect of this is that the blind person is not treated in terms of the real situation, that is in terms of his/her personal traits or abilities, but rather in terms of others' misconceptions. If the blind person adds to this his/her own negative feelings, the result to self-worth might be devastating.

2.6.2 Personal independence

Blindness may imply a loss of personal independence in almost every area of functioning in a person's life. According to Carroll (1961), two opposing forces are at work in regard to the issue of independence: the desire for independence and its freedom, and the desire for dependence and its protection. Consequently blind people experience mixed feelings regarding this issue. He suggests that the solution is for blind people to make peace with the fact that sometimes dependence might have to be forced on them. Even though they will wish that it were different, they must accept it when necessary, while not seeking it when it is not. However, he remarks that in practise, few people have such maturity (Carroll, 1961).

According to French (1993c), independence is generally considered by others to be something disabled people desire at all costs. She argues that the idea of

independence can be overdone, restricting rather than enriching the lives of disabled people. She regards this tendency to insist on independence as nothing but a form of oppression, individualising disability rather than viewing it in social terms. Oliver (1990) believes that individualising disability has a depoliticising effect which is politically convenient, placing the onus firmly on disabled people to cope and adapt in a society adapted to the needs of non-disabled people (French, 1993c).

2.6.3 Loss of light

There is a commonly held belief that blind people live in darkness. According to Carroll (1961), although analogies of light and darkness are frequently applied to sight and blindness, light is not sight itself, and blind people do not live in perpetual darkness. However, this connection between blindness and darkness can be so powerful that even blind people themselves sometimes may accept the belief without re-evaluating the situation for themselves (Carroll, 1961).

On a deeper level, some blind people might have unconsciously linked blindness to troublesome and upsetting ideas and images of darkness. For example, if perhaps because of childhood associations, night has for the blind person the meaning of separation from love, such an individual may acutely feel the loss of light security contributing to such a person spending their life 'in the dark', possibly feeling separated from others and their love (Carroll, 1961).

2.6.4 Loss of environment

It is obvious that sight, in the first place, orientates a person to his/her environment, or even reality. It could be argued that blindness, as a severing of a major link with reality may be seen as a kind of 'being separate' from the things around the blind person, including from the environment (Carroll, 1961). A sudden or gradual loss of sight, therefore, may result in feelings of being disconnected or even alienated from one's environment or reality. Thus, sight not only identifies objects, but enters people among them.

A further loss related to the loss of environment is that of the visual background to the world in which people live. For blind people, this constitutes a loss of an awareness of the living, three-dimensional world, leading to the foregoing of the

continuous screening of information which takes place below the level of consciousness. This means that blind people lose the shadows and highlights, forms and textures, colours and movements which prevent monotony, and as a result, can find themselves in a never-changing and therefore dull visual vacuum or void (Carroll, 1961).

2.6.5 Loss of everyday skills

The blind person may experience a host of a thousand repeated frustrations in the course of his/her daily life, which serves as a constant reminder of blindness. These include simple basic functions such as picking up from the floor a small object that has slipped from one's hand, selecting matching colours when dressing, getting to the phone before it stops ringing and many more seemingly small inconveniences. However, the loss can nevertheless be seen as a major one, because of the multiplication of thousands of these small inconveniences (Carroll, 1961).

2.6.6 Loss of mobility

For the blind person, mobility means much more than walking, it refers to the general ability to get about; it is the difference between total immobility and dependence and being fully part of life. The loss of mobility is not simply a matter of mere inconvenience; it could have a devastating effect on a blind person's life, negatively impacting on career, recreation, and social adequacy (Carroll, 1961).

2.6.7 Loss of the ease of the written word, and the role of technology

Reading and writing are essential skills in terms of a career, keeping up with information, social activity, as well as recreation. The loss of these skills could literally mean total isolation from the world. This may be particularly applicable to those who lose their sight later in life. Unlike congenitally blind people who more than likely would have been taught Braille since childhood, such people may experience difficulties in accessing the means to read and write.

According to Carroll (1961), such blind people have lost the ease of written communication. In the first place, this means that they have lost the ability to read and write in the normal way. However, it implies more than this. Today, many tools are available to restore various aspects of written communication. Such devices

require basic computer literacy and are extremely expensive. Also, extensive training may be required. In developing countries, including South Africa, funding for these devices is sometimes problematic, and the necessary training is often too expensive or simply not available.

Nevertheless, Computer Mediated Communication (CMC) is a reality today and has the power to change the lives of blind people. Amongst other things, blind people are able to read, write, send and receive emails, and surf the Internet. Such media technologies are liberating and enabling, because apart from the obvious implications for career opportunities, amongst other benefits, CMC offers independent access to information and entertainment, extending the range and reach of blind people's experience. It enables participation in all kinds of areas, offering a sense of community and interconnectedness, as well as a range of social interactions (Goggin & Newell, 2003, in Stadler, 2006).

In terms of social interaction, the availability of CMC has been nothing less than revolutionary; communicating in an online environment avoids the prejudices that are often triggered by visible signs of disability. The Internet allows people to communicate with each other across great distances, form relationships irrespective of age, race, gender and ability, and create online communities that are not limited by geographical location (Stadler, 2006).

CMC makes it possible for people to separate their physical bodies from their social identities. It involves communicating with others in a virtual environment in which the body can be absent (Goggin & Newell, 2003, in Stadler, 2006).

2.6.8 Loss of the ease of spoken communication

On the face of it, one might not link this loss to blindness. Contrary to what one might think though, this is a real loss, as the degree to which lip-reading plays a part in ordinary listening is not generally realised, nor is the vital role of gesture and facial expression in clarifying or modifying the meaning of speech (Carroll, 1961). In addition to this, the blind person may also suffer many social uncertainties - how loud to speak; whether he/she is being addressed; where the other person is; whether his/her companion has left him/her; inability to make eye-contact (Rowland, 1985).

Furthermore, the ability to make inferences and judgements based upon available visual information is essential for effective communication. Complicating social interaction even more, being unable to observe people and other clues within the social environment directly, the blind person may find him- or herself somewhat hampered in the means of obtaining social information relating to work, hobbies, environment, or even just gossip, lagging behind in the circle of his/her friends, neighbours, and associates. In short, the effect of this is that the blind person's knowledge may suffer cumulatively and this may have an effect on how such a person functions socially and is viewed by others (Carroll, 1961).

2.6.9 Loss of visual appreciation of the pleasurable and of beauty

This is the loss of the visual component in the perception of what is pleasurable and/or beautiful. It includes aspects ranging from the tempting display of food that stimulates appetite to beholding the sex object (Carroll, 1961). It is of course relevant here whether the person is congenitally blind or lost their sight later in life; congenitally blind people have never experienced the visual component in the perception of pleasure, so it can be argued that this does not constitute a loss for them.

Personal factors also play a role, in that the visual component in the perception of pleasurable objects and of beauty may differ from person to person. This loss is seldom mentioned, partly because the perception of pleasure, in particular in relation to the sex object, may not be a topic easily spoken about by most people. In terms of the visual perception of the beautiful, beauty can of course still be perceived via other people's descriptions and also by means of the other senses. Carroll (1961) remarks that sighted people almost invariably mention this loss, but blind people rarely do, possibly because this loss is outweighed by other losses or it might be too keenly felt. Alternatively, the visual component in the perception of pleasure might not be experienced as a loss by most blind people.

2.7 Belief system/religion/locus of control

Living with blindness may have an impact on an individual's worldview or belief system. Conversely, an individual's worldview or belief system may impact on how such a blind person lives with blindness. This may influence the way he/she copes

with life and life's challenges. When blind people believe that their behaviour is informed and guided by an external factor such as God or fate, a possible implication of this may be that their actions are contingent on events outside their personal control (Neill, 2006).

For religious people (those who believe in a God), the underlying belief is that God is ultimately in control; suffering in this life is in His hands and plan, should be borne with fortitude and will be rewarded in a perfect life hereafter. Furthermore, the believer depends on God for strength and help. Thus, there might be a subtle acceptance of one's lot possibly without much of a desire or attempt to do anything about it for oneself (Neill, 2006).

Those who are not religious, but who see fate at the root of their trouble, would not look to God for help or strength. Nevertheless, what has happened to them, their blindness, is seen as out of their control. They are at the mercy of fate (Neill, 2006).

2.8 Living with disability: Some reflections of disabled writers

By drawing on some life experiences and personal reactions of some disabled writers, this next section further investigates the real embodied experience of living with impairment. The aim is to contribute towards establishing a framework within which to explore the personal experiences of the participants. At the risk of becoming repetitive, it is necessary to mention again that in as much as any loss or personal suffering is articulated here, it is not the intention to ascribe loss and suffering to disabled people or to suggest that these experiences belong to all disabled people. Furthermore, this approach is limited in as much as personal experiences and responses can never be separated from the personality and biography of the person they concern. Also, experiences will vary according to the individual's impairment. However, with these limitations in mind, there is a certain confidence that disabled people will identify with what is described (French, 1993b).

Watermeyer (2013) remarks that the very nature of impairment is mysterious, unexplored and unchallenged. He observes that, in his own life, his inability to read in the normal way seemed like a good reason for disqualification as a student. This, however, was partially changed in the public realm by social model politics. Yet his

own experience of impairment remained present and ever mysterious. He poses some searching questions about the experience of impairment. Questions like: What is its meaning, what is its impact, is anyone to blame for exclusion, what is it like for other people, what can we allow ourselves to feel, what can one reasonably expect from one's life, oneself, one's career or relationships (Watermeyer, 2013)?

With regard to the question of what it means or what it is like to be impaired, Murphy (1990) remarks that most people seldom ask questions about the very essence of impairment. He says: "A few have asked me what caused my condition, and, after hearing the answer, have looked as though they wished they hadn't. After all, tumors can happen to anybody, even to them" (Murphy, 1990, p. 326). Murphy remarks that even physicians seldom ask, being only interested in the body and reducing experience to neat distinctions of black or white, whilst ignoring the "broad range of ideation and emotion that always accompanies disability" (Murphy, 1990, p. 326).

Murphy's (1990) experience is typical of the medical model which holds that the 'problem' arises wholly from some anatomic or physiological disorder and is correctible by standard modes of therapy, with the full subjective states of the patient being of little concern. The patient's feelings and emotions, what goes on inside his/her head, belong in another department and are not part of their terrain. Any sign of serious psychological problems precipitates a referral to an appropriate specialist.

Regarding the emotional and social well-being of disabled people, French (1993b), a visually impaired disability writer, suggests that some disabled people are socially compelled to deny their impairment. However, she does not regard this denial as a form of psychopathology. She argues that from earliest childhood, denial of disability is totally rational given the situations disabled people find themselves in and that it is a mistake to regard it as a psychopathological reaction or a character flaw. Disabled people deny their disabilities for social, economic and emotional survival and they do so at considerable cost to their sense of self and their identities.

French (1993b) explores and illustrates this point by relating experiences from her own life as a visually impaired person. The roots of this denial, she suggests, are to be found in childhood, in the anxiety of adults and others emotionally involved with

the issue of the degree of sight the child still possesses. She observes: "Having adults pretend that I could see more than I could and having to acquiesce in the pretence, was a theme throughout my childhood" (French, 1993b, p. 1). As a child, she had to deny her disability by saying that she could see when she could not, in order to protect other people's feelings and to allay their anxiety.

Furthermore, French (1993b) experienced pressure from anxious relatives to look and act normal. She relates that others became very perturbed if ever she looked 'abnormal'. She says: "Being told to open my eyes and straighten my face, when all I was doing was trying to see, made me feel ugly and separate" (French, 1993b, p. 1). Others who were not emotionally involved with whether she could see or not also contributed to this denial by their disbelief. In essence, such people were confused and unable to cope with the ambiguities of partial sight and were not prepared to take her word on the matter. She relates:

One example of this occurred in the tiny country primary school that I attended. On warm, sunny days we had our lessons outdoors where, because of the strong sunlight, I could not see to read, write or draw. It was only when the two teachers realised I was having similar difficulties eating my dinner that they began to doubt their interpretation that I was a malingerer. (French, 1993b, p. 1)

When unsuitable treats were organised, events not conducive to a visually impaired child, she experienced a strong sense of spoiling other people's fun. Explaining her situation without appearing disagreeable, sullen and rude was so problematic that she usually denied her disability and suffered in silence. She says that all of this taught her the following from a very early age:

...while the adults were working themselves up about whether or not I could see rainbows, my own anxieties must never be shared. These anxieties were numerous and centered on getting lost, being slow, not managing and, above all, looking stupid and displaying fear. I tried very hard to be 'normal', to be anonymous and to merge with the crowd. (French, 1993b, p. 2)

She was urged to join other children in various activities so as 'not to miss out on the fun'. However, she did not know how much others noticed her difficulties, although

they were never discussed directly with her and she was never teased. This lack of communication, nevertheless, gave her a powerful unspoken message that her disability must be denied.

By denying the reality of her disability she protected herself from the anxiety, disapproval, frustration and disappointment of the adults in her life (French, 1993b). She says:

Like most children I wanted their acceptance, approval and warmth and quickly learned that this could best be gained by colluding with their perceptions of my situation. I denied my disability in response to their denial, which was often motivated by a benign attempt to integrate me in a world which they perceived as fixed. My denial of disability was thus not a psychopathological reaction, but a sensible and rational response to the peculiar situation I was in. (French, 1993b, p. 2)

Despite the harshness of institutional life, she experienced attending a special school as a 'relief' because, "For the first time in my life, I was a standard product and it felt very good" (French, 1993b, p. 2). Here the reality of the visually impaired children's disabilities was not openly denied, yet the only thing guaranteed to really enthuse the staff was the slightest glimmer of hope that their sight could be improved. She relates: "Contact lenses were an innovation at this time, and children who had previously been virtually ignored were nurtured, encouraged and congratulated, as they learned to cope with them, and were told how good they looked without their glasses on" (French, 1993b, p. 2).

Being encouraged, even forced, to use expensive equipment that made no difference to their condition, that did not work, and sometimes even made it worse, conveyed the message: "You are not acceptable as you are" (French, 1993b, p. 3). Lack of sight also became an issue at the special school during the rare and clumsy attempts to force integration with able-bodied children. The worst possible activity was usually chosen (for example, ball games). The choice of highly visual activities may have been a deliberate denial of the visually impaired children's disabilities (French, 1993b).

As well as denying the reality of their disabilities, disabled children are frequently forced to deny painful feelings associated with their experiences. She says: “we knew exactly how we must behave. Protecting the feelings of the adults we cared about became an arduous responsibility which we exercised with care” (French, 1993b, p. 3). She remarks that bravery and stoicism were demanded by the institution too, saying:

Any outward expression of sadness was not merely ridiculed and scorned, it was simply not allowed. Any hint of dejection led to stern reminders that, unlike most children, we were highly privileged to be living in such a splendid house with such fantastic grounds, an honour which was clearly not our due. (French, 1993b, p. 3)

At the next school she attended, she experienced in essence the same message, although differently packaged; the ethos was different but the underlying message was the same: ‘deny your disability’ (French, 1993b). She relates that the headmaster, a pioneer in the education of partially sighted children, appeared to have a genuine belief not only that such children were as good as everyone else, but that they were possibly even better. He encouraged the children to regard themselves as sighted and steered them away from any connection with blindness. She says:

In many ways his attitudes and behaviour were refreshing, yet he placed the onus to achieve and succeed entirely on ourselves; there was never any suggestion that the world could adapt, or that our needs could or should be accommodated. The underlying message was always the same: ‘Be superhuman and deny your disability’. (French, 1993b, p. 4)

Becoming more subtle and harder to perceive, most of these pressures to deny disability persist in adulthood. Also, many of the problems experienced by disabled adults are similar to those experienced by disabled children. Disabled people frequently provoke anxiety and embarrassment in others simply by their presence. Consequently, in order to safeguard the feelings of others, disabled adults are often compelled to deny their disabilities and needs, at great cost to themselves. For example, in attempting to do this, it is not unusual for disabled people to endure boredom or distress, and reassuring phrases, such as ‘I’m all right’ or ‘Don’t worry

about me' become almost automatic (French, 1993b). She observes: "They may, for example, sit through lectures without hearing or seeing rather than embarrass the lecturer, or endure being carried rather than demanding an accessible venue" (French, 1993b, p. 4).

According to French (1993b), one of the reasons disabled people react in this way, rather than being assertive about their disabilities, is to avoid the disapproval, rejection and adverse labelling of others, just as they did when they were children. This is because disabled people's reactions are viewed as the result of their impairments, rather than as the result of the ways they were treated. Being 'up front' about disability and the needs which emanate from it can easily lead disabled people to be labelled awkward, selfish or warped. French (1993b) remarks that such labelling is very difficult to endure without becoming guilty, anxious and depressed (French, 1993b). She says: "it eats away at our confidence, undermining our courage and leading us to deny our disabilities" (French, 1993b, p. 4).

Non-disabled people often respond with disbelief when disabled people attempt to convey the reality of their disabilities. French relates: "If, for example, I try to explain my difficulty in coping with new environments, the usual response is, 'Don't worry we all get lost' or 'It looks as if you're doing fine to me'." Or, "when I try to convey the feelings of isolation associated with not recognising people or not knowing what is going on around me, the usual response is 'You will in time' or 'It took me ages too'" (French, 1993b, p. 4).

French (1993b) points out that this type of response renders disabled people just like everyone else. She remarks that for those disabled from birth or early childhood, where there is no experience of normality with which to compare their situation, knowing how different they really are is problematic, making it easy to become confused and to have their confidence undermined when others insist that such disabled people are just the same. French says:

An example of denial through disbelief occurred when I was studying a statistics component as part of a course in psychology. I could see absolutely nothing of what was going on in the lectures and yet my frequent and articulate requests for help were met with the response that all students panic

about statistics and that everything would work out fine in the end. As it happens it did, but only after spending many hours with a private tutor. As people are generally not too concerned about how we 'got there', our successes serve to reinforce the erroneous assumption that we really are 'just like everyone else'. When I finally passed the examination, the lecturer concerned informed me, in a jocular and patronising way that my worries had clearly been unfounded! (French, 1993b, p. 5)

French (1993) observes that a further reaction, often associated with the belief that disabled people are really no different, is that because disabled people's problems are no greater than anyone else's, they do not deserve any special treatment or consideration. She says that people who react in this way view disabled people as "whingeing and ungrateful complainers whenever such disabled people assert themselves, explain their disabilities, ask that their needs be met or demand their rights" (French, 1993b, p. 5). This kind of reaction can easily give rise to feelings of insecurity and doubt in the disabled person.

A further aspect of relevance is that often others are unable to accept or respond to the fact that disabled people's impairments can vary in severity and can give rise to different types of disability. Often, attempts to defy or challenge this perception is futile; in the interests of simply getting on with life and its various activities, disabled people may therefore rather choose to comply and, in doing so, deny the reality of their disabilities. According to French (1993b), when disabled people attempt to gain employment, deciding whether or not to deny disability probably comes most clearly to the fore. She remarks that before the days of equal opportunity policies, it was fairly common to be told outright, that in order to be accepted, the job must be done in exactly the same way as everyone else.

French (1993b) is of the opinion that in many ways this was easier to deal with than the situation now, where equal opportunity policies have at the same time raised expectations and pushed negative attitudes underground whereas, in reality, little has changed. Although there is no way of proving it, denial of disability is probably fundamental to gaining employment, at least to some extent. It is likely that

difficulties may be minimised and the person may portray him- herself in a positive light.

A further aspect regarding the work environment is mentioned. French (1993b) relates that once in the job, people sometimes decide that certain tasks, which the disabled person can perform quite adequately, are beyond him/her, while at the same time refusing to relieve the disabled person of that which he/she cannot do. According to French (1993b), this amounts to the nature of the disabled person's disability being defined by other people. Furthermore, when 'special' equipment or consideration at work is given to disabled people, it is regarded as a charitable act or donation for which such a disabled person should be grateful and beholden. She says that such behaviour delivers two distinct messages to disabled people, firstly, that the disabled person has failed to be 'normal' (and has therefore failed) and, secondly, that such a disabled person must ask for nothing more (French 1993b).

2.9 Summary

In summary, in this chapter the various approaches to the meaning of disability (with a focus on blindness), were explored in terms of the social construction of the concept and the embodied experience, that is the real, actual experience, of living with blindness. The exploration initially focused on the medical model, which links disability to impairment, and then shifted to the social model. This model challenged and transcended traditional, individualising medical approaches, viewing disability as constructed and as a form of social oppression.

The chapter then progressed to a discussion of the embodied experience of disability. As a result of the social constructionist character of social modelist theorising, the body (the real) has been removed from the definition of disability, in the process removing the body from the experience of disability.

Along with those who criticised the social model's neglect of the personal experience of disability, the chapter attempted to pay much needed attention to the real experience of living with blindness. This was done in terms of an investigation of the psycho-emotional dimensions of blindness, which include the impact of sighted responses in the form of hidden assumptions and psychic investments, as well as

the role of living with impairment, including the aspect of loss and suffering. Some losses associated with living with blindness were discussed.

In the last section of the chapter some life experiences and personal reactions of disabled writers were included. This was included in order to support further investigation of the embodied experience of living with impairment and towards establishing a framework within which to explore the personal experiences of the participants.

2.10 Aims and Rationale

This section offers a short summary of the aims and rationale of the study, and of the various issues impacting on the meaning of disability.

2.10.1 Rationale of the study

The overall rationale of the study was to raise awareness concerning the plight of blind people amidst an essentially disablist society. In the first place, the aim was to clarify the meaning of the concept for the participants as well as for others, whilst at the same time, making the participants aware that they can be part of a collective struggle which is capable of making fundamental challenges to society.

Further, the intention was to recognise and acknowledge the real suffering of people living with impairment. To this end, the study attempted to provide a safe space for the participants to share accounts of loss and suffering related to living with blindness. In addition, it was hoped that the study could make an academic contribution to the topic of Disability Studies in South Africa.

2.10.2 Aims and objectives

The study aimed to explore the concept of disability in terms of its social construction and in terms of the real experience of disability, inclusive of an exploration of the personal experience of living with blindness. Regarding the social construction of the concept, it is argued that its meaning is underpinned and informed by societal discourses in the form of the medical model which links disability with impairment, and the social model which views disability in terms of barriers which may be social, environmental and economic.

The aim was to explore the embodied or real experience of disability in terms of the role of others' attitudes, and the impact of living with impairment on the participants' emotional and social lives. This experience included the possible losses that may be associated with living with blindness within a disablist society.

The overarching research question in this study is:
What is the embodied experience of being blind?

Further, the study attempts to address the following sub-questions:

1. How do assumptions regarding blindness and blind people affect the understanding and treatment of blind people?
2. What is the nature and effect of these assumptions?
3. How does the experience of living with blindness impact on the emotional and social well-being of blind people?

Chapter 3: Methodology

3.1 Research design

A research design is a plan according to which the research will be conducted and involves several decisions, the main decision being which type of design should be used to study the particular topic. This decision should be informed by the worldview or assumptions the researcher brings to the study; procedures of inquiry (called strategies); and specific methods of data collection, analysis, and interpretation. The selection of a research design is also based on the nature of the research problem or issue being addressed (Creswell, 2009).

In this study, the researcher sought to explore the meaning of disability, focussing specifically on the real experience of living with blindness. It investigated certain phenomena, what these are about, what they appear like on the surface and also what their other levels of meaning may be; in other words, the study investigated the qualities of phenomena rather than the quantities (Henning, van Rensburg & Smit, 2004). Therefore, it was decided to rather make use of a qualitative research design. This approach was chosen instead of using a quantitative research design, which is a means for testing objective theories by examining the relationship among variables which then can be measured on instruments so that numbered data can be analysed statistically (Creswell, 2009).

Further, this decision was taken because the issue being explored, that is, the impact that living with blindness amidst a disablist society has on the lives of blind people, has personal as well as social dimensions. Qualitative research is a means of exploring and understanding the meaning individuals or groups ascribe to a particular social or human problem (Creswell, 2009), and therefore served as a suitable research design. In such a qualitative research design, the process of research involves emerging questions and procedures; data typically collected in the participant's setting; data analysis inductively building from particulars to general themes; and the researcher making interpretations of the meaning of the data (Creswell, 2009).

As mentioned earlier, any research is underpinned by certain philosophical assumptions, that is, by a basic set of beliefs that frame and guide action. It is important for the researcher to acknowledge her own theoretical positions and values in relation to her research and that the theoretical framework and methods match what the researcher wants to know. The philosophical assumptions underpinning the research are linked to distinct methods or procedures (Creswell, 2009).

The present research, in seeking to explore the real experience of living with blindness amidst a disablist society, is best suited to a qualitative methodology. Although a rationale of the study was to raise awareness concerning the plight of blind people within society, the researcher did not view the research only or even primarily as a tool for advocacy or as a means of improving social justice for blind people.

The researcher set out to explore the participants' experience of living with blindness in order to describe, understand and interpret their meanings, ultimately towards facilitating a better understanding of what it meant for the participants to be disabled. The intention further was to contribute to the process of negotiating a way for people living with impairment in a disablist world to acknowledge having experiences that influence their psychological and emotional well-being without being defined by these experiences. To this end, the study attempted to provide a safe space for participants to share with others a personal account of living with blindness.

Therefore, the study was situated largely in an interpretivist research paradigm; such a paradigm emphasises experience and interpretation, is fundamentally concerned with meaning and seeks to understand people's definitions and understandings of situations (Henning et al., 2004). The study was descriptive and aimed to capture aspects of the lives of the participants in order to understand and to interpret the meaning of the reality of participants from their own viewpoints.

Furthermore, the researcher also inquired into the way social meaning comes about in certain discourses and how these discourses were maintained. In line with interpretive philosophy, the researcher is not entirely separate from the subject of the

research (Henning et al., 2004). Henning et al. (2004) argue that as the researcher explores participants' experiences and meanings, using the human mind to do so, he or she cannot be completely separate from what is being investigated. The researcher can be considered to have been an 'insider' during the process of conducting the research (Henning et al., 2004). It was thus important for the researcher to reflect critically on her own perspective and how this related to her interpretation of the data.

The methodological implications of an interpretive framework include open interviewing, idiographic descriptions and qualitative data analysis (Henning et al., 2004). In the case of the present study, qualitative data in the form of the participants' email contributions was collected, analysed and interpreted using thematic analysis.

In the decision of which type of design should be used for the study, the research problem should also be considered. The over-arching research problem in this study was the issue of disablism (others' negative attitudes to disabled people). Based on the literature review, it transpired that especially in South Africa, little research has been conducted on this issue and that disablism is often misunderstood and not viewed as a form of discrimination. Therefore, the study merited an exploratory qualitative approach which is useful when the researcher does not know the important variables to examine (Creswell, 2009).

3.2 Sampling

3.2.1 Recruitment

In the matter of locating the research participants in the present study, nine blind people were invited to share some of their everyday experiences of living with blindness. Being qualitative research, purposive and convenience sampling were chosen to identify the participants. The sample was selected based on their availability and on the researcher's judgment and the purpose of the research (Trochim, 2006).

Purposive sampling is a non-probability sampling technique. Prospective participants are chosen because of the qualities they possess. This non-random technique needs

neither underlying theories, nor a set number of participants. It does not provide a generalisable sample, but because this project was descriptive and exploratory in nature, such a limited sample is still useful. Simply put, the researcher decides what needs to be known and sets out to find people who can and are willing to provide the information on the basis of knowledge or experience (Trochim, 2006).

In the search for potential participants, an initial telephonic inquiry was made with the relevant gatekeepers: The SA National Council for the Blind, Tape Aids for the Blind and a retired chairperson of the SA Blind Workers Association. This was followed by a letter (Appendix B) setting out the general objectives and aims of the research. Tape Aids for the Blind informed the researcher that, for reasons of confidentiality, they were not able to reveal the names of any members. The SA National Council for the Blind did not respond timeously with a list of names, but the retired chairperson of the SA Blind Workers Association supplied a list of 12 names and email addresses of prospective participants.

The researcher contacted all 12 prospective participants. She emailed them a letter (Appendix C) introducing herself. In this letter she explained to them that she intended to investigate the experience of living with blindness in order to raise awareness concerning the position of blind people within society. As an initial step in defining the sample, the researcher invited all 12 prospective participants to email her a short paragraph about him- or herself. One prospective participant said that he did not want to participate because of time constraints, while a further two did not respond to the request for a short paragraph. Nine participants responded with short paragraphs and expressed an eagerness to participate. These nine participants formed the sample of the study.

In the recruitment and sampling process, the researchers' aim was to find participants with experience of being blind. The participants were identified on the basis of their being blind and being comfortable to talk about the experience of living with blindness, as well as having time to devote to the research.

Although race, language social class, age and gender were not considered in the selection process, there are dimensions of the purposeful and convenience nature of

the sample that influenced the final characteristics of the sample. An inclusion criterion was for the participants to have access to a computer as well as to assistive technology for the blind as they were required to respond via email. The fact that a blind person has access to a computer and assistive technology for the blind does not necessarily imply a certain income group, class or race. Disability can cut across all such social categories. Thus, access to assistive technology for the blind does not necessarily suggest that all the participants are from a similar economic or social background. On the one hand, such technology is expensive and thus the sampling process may have accessed a particular social category. On the other hand, in some instances, such technology is made freely available to blind students and employees. At least two of the participants were unemployed and living with relatives, yet they both had access to a computer and assistive technology for the blind.

The fact that the participants used assistive technology for the blind also meant that they were comfortable to communicate in English, as assistive technology for the blind is not available in any of the other official languages in South Africa. For eight of the participants, all email communication with the participants was in English. One of the participants, Participant C, responded in Afrikaans. The researcher had this contribution translated into English by a first-language Afrikaans speaker who is also fluent in English. The original, as well as the translated versions, were read to the researcher. Being Afrikaans-speaking herself, she was able to verify the translations. Notwithstanding his difficulty with English, the same participant made a special effort and submitted a further email contribution in English.

Whether a person was congenitally blind or became blind later in life was not one of the inclusion criteria in this study. The intention was to explore the everyday experiences of blind people and not to draw any comparisons between the experiences of congenitally blind people and those who lost their sight later in life. However, as far as the experience of some of the possible losses related to living with blindness is concerned, it may be of relevance when a person became blind. In such instances this was noted. Without being asked, most of the participants indicated to the researcher when and how they lost their sight. Only two of the

participants, Participant D2 and Participant A did not indicate when and how they became blind.

The aim of the study was to explore the everyday experience of blind people to contribute towards a better understanding of what it means to live with blindness within one's community. Given the purposive and convenience nature of the sample, the experiences of the nine blind participants were not viewed as representative of the experiences of all blind people; however as discussed above, they could be transferable to similar people in similar settings.

3.2.2 Description of the participants

The researcher did not explicitly set out to gather a full set of demographic data on each participant. She simply invited them to write a paragraph about themselves. This they duly did, with the exception of Participant A, who disclosed very little about himself; apart from his name and surname, he merely informed the researcher that he is 'blind/visually impaired' and 'is working in the field of disability'. The remaining participants for the most part supplied the researcher with sufficient and relevant biographical details. Thus, the sample comprised three women and six men. The participants ranged in age from 26 to 70 years old and from highly qualified to holding no formal qualification.

The researcher did not explicitly set out to gather full demographic data because the focus of the study was on the experience of living with blindness and not so much on the biographical information, which was considered to be of secondary significance. A degree of sensitivity was also required both in approaching the potential participants and in making demands which may have been seen as intrusive.

The participants are briefly introduced below (see Table 1). Their identities are protected, using a coding system to ensure anonymity. The coding involved using the first letter of the participant's name. There were three male participants whose name began with a D and they are referred to as D1, D2 and D3. Of the three female participants, two of their names began with the same letter; hence they are coded as M1 and M2. Further, the researcher ranked them from oldest to youngest, such that D1 is the oldest of the males and M1 the oldest woman.

Table 1: Demographic characteristics of the participants

Participant	Sex	Age	Cause of blindness	Number of contributions
A	male	Unknown	Unknown	1
C	male	48	Retinal degeneration	3
D1	male	70	Retinal degeneration	1
D2	male	57	Unknown	5
D3	male	26	Brain tumour (aged 10 years)	3
J	male	38	Accident (2005)	3
L	female	28	Not congenitally blind	3
M1	female	60	Retinal degeneration	4
M2	female	45	'Visually impaired'	1

Participant A, as mentioned above, did not reveal too much about himself. Apart from briefly responding to the two questions that were put to the participants, he provided a long list of myths and assumptions about disability and blindness. The researcher felt that this list did not necessarily reflect personal experience and therefore did not use material from the list for the study. Nevertheless, Participant A did make a valuable contribution to the study, in that he raised an aspect of social interaction that was not addressed by most of the other participants.

Participant C is male, 48 years old, a father and married. He lost his sight gradually due to retinal degeneration. He has no formal qualifications but he possesses technical and computer skills. He worked as computer skills trainer for other blind people. He left this job to start his own training business which was not successful. Currently, he and his family live on a relative's farm where he helps with farming chores. In his spare time, he is doing a theology course with the idea of eventually becoming a pastor.

Participant D1 is male, 70 years old, Afrikaans, member of the NG Kerk (Dutch Reformed Church) and now retired. He also suffers with retinal degeneration

(Retinitis Pigmentosa) and gradually lost his sight. He is married. He worked as a telephonist at a government office for 21 years. After that, he worked for more than 23 years in various capacities with an association for blind people.

Participant D2 is male, 57 years old, in the Dutch Reformed Church and married. He gives his qualifications as having ... “some technical qualifications, a BA in Social Sciences, and a Post-grad in Communications”. He is in charge of the switchboard at a psychiatric hospital. He did not indicate when and how he became blind.

Participant D3 is male, 26 years old, Afrikaans, Christian, and single. He lost his sight at 10 years due to a brain tumour. He has an Honours degree in music. He is a piano teacher, and is currently without work and living back at home with his parents.

Participant J is 38 years old and has been blind since 2005 as the result of a motorbike accident. He calls himself “Blind Biker”. His home languages are a mixture of English and Afrikaans and his religious affiliation is “none/Atheist/Agnostic”. He is a computer programmer/software and website developer and is married.

Participant L is female, 28 years old, English/Afrikaans speaking, Christian and married. She recently qualified as a psychologist and is currently working on her D.Phil. in psychology. She indicated that she was not congenitally blind but did not supply information relating to how she lost her sight.

Participant M1 is female, 60 years old, married, a mother and grandmother. She is retired. She lost her sight gradually as a result of retinal degeneration. She completed her matriculation examination later in life. She worked as a telephonist, and later as a call centre operator.

Participant M2 is female, 45 years old, married, a mother, Afrikaans and Dutch Reformed. She did not supply information relating to how she lost her sight. However, she calls herself visually impaired and not blind. She is a project Administrator.

3.3 Ethical considerations

To comply with ethical requirements, ethical approval for this study was granted from the University of KwaZulu-Natal, Human and Social Sciences Research Ethics Committee (see Appendix A). In line with the Belmont Report of ethical guidelines for research and the American Psychology Association research code, the following principles of ethics were considered.

3.3.1 Autonomy of participants

A detailed letter which explained the objective, aims and nature of the research was sent to prospective participants (Appendix D). In this letter, the participants were informed that they were not in any way being forced to take part in the study (their participation was voluntary) and that they could discontinue their participation at any time without penalties or being prejudiced in any way. The researcher also informed them that emailing her the short paragraph and answering her questions would be sufficient to indicate their consent to participate in the research.

3.3.2 The principle of trust

Participants were assured that their email contributions would remain confidential. Because the topic of disability might be regarded as sensitive and to avoid putting any participant at risk, it was necessary to mask the names of people, places, and activities (Creswell, 2009). This was communicated to the prospective participants. To this effect, each participant was given an anonymous user name, so that no one would be able to link them to their email contributions. The researcher assured them that only she would have access to the information and that after the research had been completed, their email contributions would be expunged.

3.3.3 Nonmaleficence

Although blind people might be seen as a vulnerable population, the researcher believes that this study did not present any grave harm to participants. The participants who were invited to take part in the research were those who were comfortable to engage with the topic and did so via email contributions. They were fully aware of what participation would entail through a letter detailing the research aim and process (see Appendix D).

The letter (Appendix D) also raised the possibility of participants being psychologically distressed as they reflected on their histories as blind people, or on their everyday experiences of living with a disability. In the letter, the researcher conveyed to the participants that should anyone have any concerns during the course of the research process, their participation could stop immediately. In this regard, the researcher secured an appointment with the social worker at the South African National Council for the Blind, and after explaining the objective, aims and nature of the research, this social worker consented to the participants contacting her should they need any assistance or referral for further support.

3.3.4 Beneficence

This study offered indirect as well as direct benefits to the participants. Firstly, raising awareness concerning the plight of disabled people in their communities, and facilitating a better understanding of what it meant to be disabled (for the participants as well as for others), would benefit the participants and their communities, as well as society at large. A more direct benefit, which could enrich and empower the participants' lives, was making the participants aware that strength could be gained from being a part of a collective struggle which was making fundamental challenges to society. Furthermore, alerting the participants that they could claim their own definitions of disability and that in doing so, they could choose to take pride in themselves, in what they are, in their difference placed a more positive value on their bodies, themselves and their lives (Morris, 1991).

Participants may also have benefited from speaking openly about their experiences of living with blindness. They may have found that this study provided a supportive environment to address some of their concerns. Part of the rationale of this study was in fact to provide a safe space for participants to share personal meanings of living with impairment in a disablist society. This was necessary because of the ever-present hints of loss-related stereotypes that are never too far from the surface in any social setting. Due to this, it is often dangerous for disabled people, including blind people, to reveal that they have suffered loss. In articulating loss and other painful parts of themselves, disabled people run the real risk of being defined in terms of these experiences.

3.4 Data collection methods

This study set out to investigate the real experience of disability, in this case blindness, in terms of the impact of others' responses to blindness and the role of living with impairment on the emotional and social well-being of blind people.

It was important to find a method of collecting data that best facilitated effective communication with the participants (Creswell, 2009). After consulting gatekeepers, for practical reasons, focus groups were considered and rejected; there is a relatively small community of blind people in South Africa and using a focus group would have meant that all the participants would have to be living in the same town or city. Furthermore, most blind people need transport to the venue, which is a time-consuming and costly undertaking. The same basic objection applied to one-on-one interviewing. The cost of interviewing the participants where they live would have been prohibitive.

Because all the participants were familiar and comfortable with using a computer, it was decided to make use of email communication. The researcher asked the participants to respond to her questions via email contributions. This was for the convenience of the researcher as well as the participants. Although telephonic interviewing might have been an option, the idea was for the participants to be able to respond free from the pressures of direct telephonic contact, which could put them on the spot and not give them the chance to reflect on their answers. Being able to respond via emails allowed the participants to think carefully before making their contributions.

The researcher emailed the participants a letter (Appendix D) which contained the instructions. They were asked to respond via email to the following topics:

- Describe an ordinary day in your life.
- Tell me about your social life; what have been your experiences in terms of social interaction?

The aim of the study was to explore and describe the real experience of disability. This guided the questions used in the data collection process and attempted to

access the participants' experiences of living with impairment and the nature and role of others' responses to their impairment.

The researcher had indicated to the participants that they could respond as often as was convenient for them and that their contributions could be of any length. Consequently, the length of the participants' contributions and the number of emails per participant also varied. Apart from the initial paragraph, some of the participants made only one contribution (Participants A, D1 and M2). However, the remaining participants all responded more than once. Participant D2 made five contributions, Participant M1 made four contributions, while the remaining participants (C, D3, J and L) each made three contributions.

Furthermore, the researcher invited the participants to raise topics of personal interest and to suggest further questions and issues for exploration (Creswell, 2009). Participant D2 raised the issue of whether a blind person ought to marry a sighted person and the issue of blind versus sighted friends. All the participants except participant A and D1 responded to this issue. The participants' responses generated a discussion between the researcher and the participants. This, in addition to all the other contributions, formed the data analysed in this study.

3.5 Data storage

After receiving each contribution, the researcher read through it and filed it in a digital file that she created for each participant. The researcher also filed her own notes relating to each contribution in the relevant file. To secure the confidentiality of the participants' identity, the files were not saved under their real names, but rather through using the coding system discussed earlier. Five years after the research has been completed, the contributions as well as the researcher's notes related to each contribution will be expunged.

3.6 Data analysis

The process of data analysis requires a degree of analytical craftsmanship; it requires capturing an understanding of the data in writing, fitting the analysis procedures with the study's methodological position and managing the analysis and

interpretation process according to the principles of the study design (Henning et al., 2004).

A qualitative form of data analysis, thematic analysis, was employed to probe the real experience of disability. The main benefit of thematic analysis is its flexibility; it is a method that stands loose of theory and epistemology, and can be applied over various theoretical and epistemological approaches (Braun & Clarke, 2006).

Furthermore, although thematic analysis is often indirectly construed as a realist/experiential method (Aronson, 1994; Roulston, 2001), it is compatible with both essentialist and constructionist paradigms. The present study adopted a largely realist method which reports experiences, meanings and the reality of the participants, and to a lesser extent a constructionist method which examines the way in which events, realities, meanings and experiences are the effects of certain discourses operating within society (Braun & Clarke, 2006).

The use of this method implies that the term 'real experience of disability', which is at the core of the present study, does not exclusively suggest an essentialist view, which is in tension with an understanding of disability as socially constructed. The body, the real, has been excluded from the definition and from the experience of disability. As a result of the social constructionist underpinning of the social model, language and discourse have been overemphasised and disability is seen as a constructed category (Hughes, 2002; Shakespeare, 1996).

However, the real, the extra-discursive, the experience of the body, in this case the personal experience of living with impairment, needs recognition. Thematic analysis provides a flexible data analysis method in order to investigate the meaning of disability with the focus on the real embodied experience, inclusive of personal experience; it is hoped that this promoted an innovative understanding of the multi-dimensional concept of disability.

A brief outline of what thematic analysis is and how it should be done is presented here. As a starting point, thematic analysis can be broadly explained as a widely used qualitative data analysis method for identifying, analysing and reporting

patterns (themes) within data and for organising and describing the data set (Braun & Clarke, 2006). Often it goes further, and can be used to interpret various aspects of the research topic (Boyatzis, 1998). In the present study, the nine blind participants described aspects of their personal experiences of living with blindness via email contributions. The participants' descriptions provided substantial data for analysis.

Adopting a theoretical approach which requires engagement with the literature prior to analysis, the researcher sought early engagement with the literature relevant to the analysis. This sensitised her to more subtle features of the data (Tuckett, 2005). Furthermore, during data collection, the researcher had already started to look for, notice and note down patterns of meaning and issues of potential interest in the data. This was part of her memoing (relevant notes were filed in the corresponding digital file).

The researcher broadly followed a simple guide or outline of the six phases of analysis provided by Braun and Clarke (2006). However, analysis was not viewed as a linear process where one simply moves from one phase to the next. Instead, it was treated as a process where movement is back and forth as needed throughout the phases (Braun & Clarke, 2006).

Making sure that she was thoroughly familiar with the content of the data, the researcher started the process by repeatedly reading through the data. She did this in an active way, searching for meanings, patterns and so on. She noted down patterns of meaning and issues of potential interest in the data for possible coding. The researcher's reading of the data was informed by the fact that she was aiming for a detailed analysis of a portion of the data, was searching for latent as well as semantic themes, and was largely theoretically driven.

The next step was to generate initial codes. After the researcher had thoroughly familiarised herself with the data and had generated a list of what was of interest in the data, she commenced with the phase of coding. Codes indicate something in the data (semantic content or latent) that appears interesting to the researcher. Codes

are “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” (Boyatzis, 1998, p. 63). Being largely theory driven, the researcher approached the data with specific questions in mind that she wanted to code around. The aim was not to code the content of the entire data set, but rather to code to identify particular features of the data set. The study investigated the real experience of living with a disability. The researcher also coded for a specific over-arching research question (the issue of disablism and the role of impairment in blind people’s lives) which linked to the more theoretical approach.

With the above in mind, the researcher worked through the data at sentence or phrase level (Henning et al., 2004). By using a marker, units of meaning were ‘marked’ and labelled in the form of crosses on either side of them. The researcher then made a list of all the codes, looking for possible groupings of the codes. She created a separate document for this list. She read the whole text again to see whether the codes made sense and whether there was some coherence, checking whether the codes could be related to the research question (Henning et al., 2004). Furthermore, as no data set is without contradiction, the researcher did not smooth out or ignore any tensions and inconsistencies within and across data items (Braun & Clarke, 2006).

The next step was to search for themes. This phase commenced when all the data had been initially coded and collated, and a long list of the different codes that had been identified across the data set was in place. To clarify what actually counts as a theme, the researcher’s judgement is necessary. Being a qualitative analysis, there was no hard and fast answer to this question. Basically, a theme captures something important about the data in relation to the research question, and represents some level of meaning within the data set (Braun & Clarke, 2006).

Another decision centred upon the level at which themes are to be identified: at a semantic or explicit level, or at a latent or interpretative level (Braun & Clarke, 2006). In the present study, a method lying between a realist approach and a constructionist method was employed. A realist approach engages with the data on the semantic level, that is, the themes are identified within the explicit or surface meanings of the

data. A constructionist method examines the latent content of the data, that is, it goes beyond the participants' words to engage with examining the underlying ideas, assumptions, conceptualisations and ideologies that are theorised as informing the participants' words. The development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorised (Braun & Clarke, 2006). Being mindful of the previous points, the researcher sorted the different codes into potential themes, and collated all the relevant coded data extracts within the identified themes.

To help organise the different codes into themes, a separate document was opened for each potential theme as well as one for the list of different codes. The researcher then played around with organising them by copying and pasting codes into potentially relevant themes. Some initial codes eventually became main themes, some formed sub-themes, and others were discarded. At the end of this phase, the researcher had in place a collection of candidate themes, sub-themes and all extracts of data that had been coded in relation to them, and had a sense of the significance of individual themes.

As coding is an on-going organic process, the need for re-coding the data set is to be expected (Braun & Clarke, 2006). With this in mind, the researcher read through the entire data set again to code any additional data within themes that had been missed in earlier coding stages. She then continued the process of further defining and refining the themes which will be presented for analysis. Thereafter, she conducted and wrote a detailed analysis for each individual theme, identifying the essence of what each theme was about (as well as the themes overall), also considering how each theme fitted into the broader story in relation to the research question (Braun & Clarke, 2006).

The last step in the process involved the final analysis and write-up of the report. Once the researcher had a clear sense of a thematic map, she used questions to guide the analysis. For example:

'What does this theme mean?' 'What are the assumptions underpinning it?'

'What are the implications of this theme?', 'What conditions are likely to have given rise to it?', 'Why do people talk about this thing in this particular way (as

opposed to other ways)?’ and ‘What is the overall story the different themes reveal about the topic?’ (Braun & Clarke, 2006, p. 53)

Once the data had been analysed according to the themes and sub-themes which emerged during the analysis phase and as related to the research question, the results were written up by the researcher as she attempted to tell the story revealed by the data. Verbatim extracts from the data which captured the essence of the point being demonstrated were used.

3.7 Reliability and validity

Reliability and validity belong to an essentially positivist epistemology. Within this epistemology, reliability can be referred to as the consistency of a measure, in that a test is considered reliable if one gets the same result repeatedly (Creswell, 2009). Validity refers to what conclusions can be drawn from the results of a measurement (Creswell, 2009). These can only be valid if the measurement actually measures what it claims to measure. Qualitative researchers tend to consider these concepts, as defined in quantitative terms, as inadequate to discuss the truth value of their findings (Kvale, 1996, Lincoln & Guba, 1985, in Henning et al., 2004).

In qualitative research, scientific rigor is established by ensuring that the research is conducted in a way that is credible, dependable, confirmable, transferable and trustworthy (Babbie & Mouton, 2008). Multiple strategies are used in order to enhance the researcher's ability to assess the accuracy of his/her findings as well as convince readers of that accuracy (Creswell, 2009).

By showing that the inferences made from the data are plausible and adequately represent the participants' responses, credibility is demonstrated. In this study, the researcher attempted to make the research credible by constantly questioning the inferences she made to ensure they were the most valid inferences that could be made. To ensure that they agreed with her findings, the researcher discussed these inferences in relation to the data with peers and her supervisor. The researcher also constantly returned to the raw data to make sure that the results were still representative of the data. In order to show where the hypothesis of the study was

confirmed and where it was not, the researcher did not ignore findings that deviated from the overall results (Phyfer, 2012).

Dependable research is research that would yield similar results if it were conducted again in a similar context with similar participants (Babbie & Mouton, 2008). In this study, in order to demonstrate that the research is dependable, the researcher attempted to ensure that the research was consistently carried out in line with standards of good qualitative research. This entailed checking for bias, as well as also for neglect, and for lack of precision in general. It also meant questioning all procedures and decisions critically, theorising and looking for (and addressing) theoretical questions that arose throughout the process (Henning et al., 2004).

Dependability is in essence an issue of method relating to the processes of sampling, data collection and analysis, that is, how things were kept consistent. In this study, in order for it to be repeatable, sufficient detail was provided on how the sampling was conducted. Regarding data collection, the same questions were asked of all the participants and all the participants were given the same instructions. Further, all the steps followed in data analysis were made clear.

Confirmability is the extent to which the results of the research, produced by this particular researcher, are held to be accurate by other researchers. Confirmability in this research was established by rendering a detailed and convincing account of the research process to readers of the research as well as by confirming results with knowledgeable peers and supervisors. By using such measures to establish scientific rigor, and demonstrating this rigor throughout the research process, the conclusions of the research were more trustworthy (Phyfer, 2012).

Although it is not possible to generalise these results in the quantitative sense because only nine blind people participated in this study, the results may, however, be transferable to other settings (Kuper, Lingard & Levinson, 2008). The transferability of the findings may be limited by the lack of detailed demographic information on the sample. However, by providing enough information in the form of a detailed and accurate description of the research process, a thorough description of the research context, and providing adequate explanation and justification for all

arguments and methodological choices, other researchers are able to make informed judgements about whether this research is transferable to other blind people in other contexts (Terre Blanche, Durrheim & Painter, 2006).

3.8 Reflexivity

Reflexivity refers to the constant self-monitoring of the impact of the researcher's own subjectivity on the research process. Possible bias is a particular threat to the methodological soundness of qualitative research and thus in order to conduct good research, it is important to outline how the researcher may have biased the results (Kuper et al., 2008).

The study has been conducted through a particular lens that is the impact of others' perceived negative attitudes on the experience of living with blindness. In the first place it must be noted that such a lens does not necessarily imply bias, it simply facilitates a research focus. However, in perusing a wide range of literature on the research topic in order to acquire insight into and understanding of the topic, it is possible that pre-existing biases, in particular the researcher's own experience of blindness, may to some extent have influenced the types of literature drawn upon and the stance with which the researcher approached the research.

Further, within data collection itself, a number of problems of bias may have occurred. The participants were aware of the topic being researched and this may have affected their responses to the research questions. By knowing the study was about raising awareness concerning the plight of blind people within society, the participants may have unduly accentuated their negative interaction with the sighted world in an unconscious attempt to provide the researcher with useful data. The data gleaned from the participants' email contributions seemed to represent the participants' unbiased views; nevertheless, it is impossible to know this for sure.

Also, for the mutual convenience of researcher and participants alike, the research was conducted via email contributions. Although this afforded the participants the opportunity to respond with careful consideration, it may have inhibited them from expressing themselves on a deeper, more spontaneous level. Because the

researcher was not able to navigate the conversation as in a face-to-face interview, certain questions were not asked and therefore not answered.

The data showed that most of the participants were reluctant to directly disclose their own intimate experiences of living with blindness and the impact that these had on their emotional well-being. Most of the participants did, however, reveal indirectly, in relating to the researcher some of their everyday experiences of living with blindness amidst a disablist society, the impact of such experiences on their emotional well-being. It was nevertheless disappointing that the participants did not feel free to talk explicitly about experiencing personal difficulties, or feeling loss of any kind or admitting openly that they had experienced suffering related to living with blindness. The reason for this could lie in not having used the right method to obtain the data, or not asking the right questions.

Generally speaking, this research posed considerable challenges because the researcher herself falls within the sample researched. It required maintaining a delicate balance between the critical requirements of objective analysis and the acknowledged limitations of her subjective inclusion. On the one hand, falling within the sample allowed for greater understanding of the participants' points of view and facilitated a greater rapport with the participants. On the other hand, it required the researcher to critically interrogate many previously held meanings and assumptions. The researcher was forced to face and interrogate such issues on a personal level. Thus, researching a dimension of life that is intimately familiar to the researcher required being extra critical of the researcher's own perceptions and experience of the phenomenon, as well as of everything the participants said.

It is contended that in the main, the researcher's close familiarity with the participants' world view did not precipitate any undue bias, and that an adequate measure of critical distance has been maintained throughout the research process. A residual possibility, however, remains that the researcher was not removed enough from the research context to avoid some element of bias.

3.9 Conclusion

In this chapter, the researcher motivated the use of a qualitative research design, situating the dissertation largely within an interpretivist paradigm. The method of obtaining the sample was described and details of the inclusion and exclusion criteria were provided. A description of the participants was presented. Information on the data collection process (i.e. the length of, and how many, email communications with each participant) was offered.

The data analysis method (thematic analysis) was discussed and a section on reliability and validity was included. Lastly, the issue of reflexivity was raised in order to manage the impact of possible bias in the form of the researcher's own subjectivity on the research process. In the next chapter, the results of the data will be presented according to the themes and sub-themes which emerged during the analysis process.

Chapter 4: Results

4.1 Introduction

In this chapter, the results of the data are presented according to the themes and sub-themes which emerged during the analysis phase and as they related to the research question. The study focused on the embodied or real experience of disability, that is, the actual experience of living with impairment (in this case, blindness). In recognising and interrogating the real experience of blindness, this study investigated the nature and role of others' responses to blindness and blind people, as well as the impact of living with impairment on the emotional and social well-being of the nine participants.

This results section will attempt to tell the story revealed by the data. Verbatim extracts from the data provide vivid examples which capture the essence of the point being demonstrated. Each extract will indicate the age and gender of the participant. Emerging from the data, the themes and sub-themes provide the premises for concluding that interactions between blind people and the sighted world are informed by hidden assumptions and that such assumptions influence the way sighted people treat blind people. Further, such assumptions are largely unconscious and reflective of underlying societal discourses regarding disability. In addition, the attitudes of sighted people regarding blindness and blind people are imbued with psychic investments. It also transpires that living with blindness impacts, in various areas, on the social and emotional well-being of blind people.

The results will be presented in terms of the two general areas which emerged out of the analysis. These are, firstly, the responses of others to blindness in the form of assumptions, stereotypes and psychic investments and, secondly, the personal experience of living with blindness inclusive of accounts of loss and personal suffering.

4.2 The responses of others – hidden assumptions

A theme common to all the participants, in fact probably the dominant theme of the study, is that in the course of living with blindness, the participants had all, in the way

that they had been treated, experienced others' hidden assumptions concerning blindness and blind people. According to Participant J (M, 38):

My biggest issue with sighted people is generally that they make assumptions about what they perceive as a disability. And, the reason for this is possibly that they're either embarrassed to have to ask, or think they might irritate me by asking, whereas these assumptions are much more irritating than if they'd had simply asked what to do.

Being largely unconscious, sighted people are not aware of such assumptions, yet they influence the way blind people are treated. On the other hand, blind people are aware of the fact that others' treatment of them is informed by certain (mostly erroneous) assumptions.

Amongst the hidden assumptions reportedly experienced by the participants were assumptions of general inability or incapacity, including the assumption that they are invisible or not worthy of being addressed because they are perceived as being unable to hear, speak, reason, understand or think. As a result, they are assumed to be always in need of assistance or only capable of doing certain jobs. A further assumption experienced by the participants is that they are regarded as not normal and as such should be pitied.

4.2.1. Assumptions of inability

The assumption underpinning most of the other assumptions mentioned by the participants is that blind people cannot do anything for themselves, or for anyone else; that is, blindness equals total inability or incapacity. All the participants, notwithstanding the fact that some of them are highly qualified and accomplished people, have reported that they are aware of and have been treated in terms of this assumption.

Participant C (M, 48) says:

Most of the normal people, as they think they are, do not think at all that blind or disabled people can do anything for themselves.

And:

It makes me fed-up if someone tells you if you can do something that they didn't believe you could do, and say, 'I take my hat off to you'... it sucks, because you and I know that the blind and the disabled can do something for themselves.

The annoyance experienced here is not only in terms of the assumption that blind people can do absolutely nothing, but rather that they are praised when performing even the most simple of tasks.

Participant D2 (M, 57) says:

To them, I was never capable of doing anything, so each and every thing I succeeded in doing, made them surprised... They cannot dream of me being able to overhaul a car engine, re-wire a car's electrical system, or house electrical wiring; they cannot imagine that I would be able to design and construct a computer, an electric gate, or anything else I have done up to now and when they see for themselves what I succeed in, they are usually amazed.

Even in the face of all his accomplishments, the impression he has is that they persist in believing that he is capable of nothing. This participant appears to be annoyed but especially despondent and discouraged.

Participant L (F, 28) relates:

The idea that blind people can't do anything for themselves is sort of a common one - for example, I had a funny example when one day a girl said to me - Sjoie, but your husband dresses you nicely. I found this real funny and when I told her that my husband doesn't dress me, and that I choose my own clothes, she was rather shocked.

She further mentions:

There is also a misconception around cooking; a lot of people cannot believe that blind people can cook and bake, they think that you will definitely burn yourself.

For someone like Participant L, who is currently working on her doctorate, to be thought of as being dressed by her husband could be demeaning if not insulting. The same is true of the assumption that she cannot cook or bake without injuring herself. The word 'funny' is used twice and could indicate ambivalence: possibly expressing both amusement and indignation.

4.2.2 The assumption that blind people are invisible

A perhaps related assumption to the previously discussed assumption is that blind people are invisible or not worthy of being addressed directly, resulting in their being treated as if unable to hear, speak, think or reason for themselves. Regarding the assumption that blind people are in some way invisible, this is what Participant D1 (M, 70) has experienced. He relates:

Often when I go to a counter, wherever it may be, and I am accompanied by a sighted person, they would talk to my companion first. Very frequently, you would be addressed through the sighted person.

This participant relates that he frequently experiences that others treat him as if he is invisible, addressing him via his sighted companion. He does not expressly mention that this treatment upsets him. This may indicate a certain degree of acceptance. Being 70 years old and having lived with blindness for most of his adult life, he has possibly reached the point where he has fully accepted his blindness. Consequently, he may be more comfortable or at ease with living with blindness amidst a largely disablist society.

Participant L, who is only 28 years old, has had the same experience. She said:

Sometimes if they want to ask you something they will ask the sighted person who is with you; this is sometimes frustrating...

Although she is much younger than Participant D1, she also appears not to be unduly negatively affected by being treated in this manner; she finds it "sometimes frustrating". This may be on account of being particularly mature for her age and therefore accepting of her blindness, or on the other hand, personal factors such as personality type, life experience, appearance, even gender may have played a role.

Participant D2 (M, 57) has experienced being treated not only as if he is invisible, but also as if he is not worthy of being addressed directly. He relates the following:

Often, I have felt to tell them I'm blind, not stupid. Before I open my mouth, many people have regarded me as stupid, rather than blind. They would, for example, ask my wife who are with me, how many sugars I want in my coffee? I think I could have answered that one myself! HAHAHA!

In this case it is not merely a question of inability, rather the participant feels that he is seen as mentally incapable, not worthy of being addressed and therefore unable to respond in the usual or normal way. As a result, he has become invisible to others; they consequently rather address the sighted companion who is regarded as mentally capable and therefore visible. This leaves him feeling indignant, hurt and angry. The 'shouted' "HAHAHA!" at the end of the quotation is an ambivalent response; on the one hand, it could denote mirth, but on the other hand, it could suggest annoyance and contempt for those who ask such thoughtless questions.

Participant D2 relates further:

Often in shops, I have found dishonest people who thought I wouldn't notice if they gave me the wrong change. What a bad mistake! Contrarily to what they may think, I immediately notice it, stay silent about it, and never return to this shop.

Again one may argue that the assumption here is that of mental incapacity; it is assumed that a blind person would not be capable of noticing or realising when he/she is cheated. This participant's response may be one of withdrawal. He does not protest or confront the other person. This may be because he lacks the confidence to do so. He may resort to the only sanction or penalty that is within his power to enforce; he removes his patronage - he never returns to the shop. It is possible that he may have experienced feelings of impotent rage. On the other hand, he may also have experienced a touch of contempt for people who behave in such a manner: noticing that he has been cheated; he retains his dignity by not mentioning it and simply never returns.

4.2.3 The assumption that blind people can only do certain jobs

This assumption overlaps with the assumption of blindness being equal to general inability or incapacity. All the participants mentioned that they are aware of the fact that certain jobs are regularly associated with blind people. Sighted people are often uninformed about what blind people can actually do and simply assume that they are only able to do certain jobs. Again, this is a reflection of certain assumptions concerning blindness, assumptions that are often not true, irrational, and even prejudicial, with the underlying assumption being that blindness implies inability.

This is illustrated by what Participant D1 (M, 70) says:

Sighted people often have the idea that the work blind persons can do are very limited. This varies, apparently according to the experience of the sighted person. Most would know about telephonists. Many would know about cane work and perhaps piano tuning. Fewer would know perhaps about physiotherapy and playing the organ in church. For the rest, you would often hear that they do not know what kind of work blind persons can do.

Participant M2 (F, 45) supplies a list of assumptions regarding blind people, including that she has experienced that blind people can only be placed as:

“Telephonist/Switchboard/Call Centre Operators.”

Participant D2 (M, 57) says:

The sighted world has a fixed idea that a blind person can do absolutely no other job than to work at a switchboard. Well, nowadays, they think we can also work at a call support centre, or is it cost centre, or whatever.

The phrase “or whatever” denotes sarcasm or contempt for people who hold such incorrect beliefs. It could also denote a negative attitude towards those who do that kind of work.

Participant L (F, 28) observes:

In some places there is also the perception that blind people are not good enough for anything else than answering telephones and weaving baskets.

According to Participant L, “This is actually a very sad misconception”. She concludes her contribution with this remark, which also reveals a level of disparagement for those uninformed and ignorant people who hold such beliefs regarding blind people:

And I don't know where people who think like this have been living for the last 20 years - today anything is possible with technology - and the necessary willpower.

The participants' responses to this assumption range from feeling that the sighted world is simply ignorant and ought to be made aware of the real situation (Participant D1, Participant L) to indignation and sarcasm (Participant D2, Participant M2). All the participants, however, are accomplished and skilled, with some holding post-graduate degrees. It is therefore not surprising that they experience it as an affront when their skills and abilities are under-valued.

Several of the participants expressed the frustrations they had experienced in relation to their careers. By means of illustrating this, Participant D3 (M, 26) says: “I finished my Honours degree ...” And: “I've been without work for about two and a half years now, and I couldn't understand it.” He further relates:

I tried to call schools if I could come and teach piano there, make backtracks, play at functions. Here and there something came along, but it vanished in a few weeks' time.

And:

I remember one day someone called me from an ad on a free classifieds site, for me to become one of his music teachers. I was so excited. At last, something! But then he said that his tutors drive from house to house. I told him, it's a bit difficult because I am blind. He was silent for a few seconds, and said: ‘Oh’. I asked him if we couldn't make a plan, but after that he didn't sound keen at all. And, I never heard from him again.

This is a very discouraging experience and may lead to the participant experiencing feelings of despondence and eventually may also result in a lack of confidence in his ability to work.

Participant D2 (M, 57) relates:

Although I am far more computer literate [Technical and Academic] than the people they do appoint, they would never even consider appointing me.

It is very discouraging to experience feeling under-valued in the workplace, when one regards oneself as better qualified than those who are actually appointed. Prolonged exposure to this situation may lead to a sense of desolation, despair and even depression.

According to Participant C (M, 48):

...people are horrible and cruel and normally think normal so they only think of themselves and don't give any disabled person a chance easily and if it happens that they give you a chance then you have to give your everything and prove yourself. And, believe me, then there are people who watch you like a hawk to see if you make a mistake so they can make you look bad to the boss or owner...

This participant has clearly had some bad experiences in the workplace. He experienced fellow workers as hyper-critical, unsympathetic and even hostile. This has caused him to be very suspicious of others. As a result, there is a certain level of resentment, bitterness and anger directed at sighted people.

Again, regarding the frustrations experienced in relation to their careers, there is a range of responses from disappointment to despondency through to anger. Obviously, personal factors play a role; personality, level of education, type of career. However notwithstanding such factors, it is clear that it is deeply discouraging for the participants to feel that they are under-valued and over-looked on account of their blindness, and often not even given a chance to prove themselves.

4.2.4 The assumption that blind people are not normal

Within society, 'normal' is generally equated with that which is average. Not being average, that is, not conforming in terms of appearance, function, behaviour or belief is seen as 'not normal'. Being regarded as different, in fact as not normal, is an

experience common to most of the participants. The participants have experienced not being regarded and treated as normal by outsiders or 'them' or 'they'. In this regard, Participant D2 (M, 57) says: "Even though I can do far more things than most of them, they still treat me as someone who cannot really be as 'normal' as them."

Being skilled and well-qualified, and by his own admission able to do "far more things than most of them", this participant is understandably indignant and regards it as an affront to still be viewed and treated by 'them' as not normal. According to Participant D3 (M, 26): "Then, when they realize that I can speak, they generally treat me somewhat normal." This participant responds to such treatment with a touch of sarcasm denoting his contempt for people who hold such misconceptions.

The participants have even experienced not being seen or treated as normal by those who know them well. This is illustrated by what Participant D3 (M, 26) says: "Well, actually some families don't even treat their family members normally." It is particularly discouraging to experience such treatment at the hands of one's own family. Such experiences can cause lasting damage to a person's emotional well-being (see later in this chapter).

Blind people, like other disabled people, are frequently the subjects of stereotyping which may be conscious or unconscious and positive or negative. Flowing from the assumption that blind people are not normal, the perception further is that they are not ordinary people going about the ordinary business of life. More often than not, they are perceived as either tragic figures deserving of pity, or as super-heroes deserving of admiration. This is also an experience common to most of the participants. On this issue, Participant D3 (M, 26) observes:

I have met with a lot of people in public... Some admire you for your ability and courage to step out into the world of sighted people and overcome every day's challenges. Others just see you as a lost, extra-terrestrial being, who found his way into the environment, and who doesn't know how to help himself.

A blind person is not affirmed by being viewed as lost and helpless, and as not belonging. It also does not serve as genuine affirmation to a capable and competent

blind person to be admired for his or her courage to simply step out into the world of sighted people and overcome everyday challenges.

Regarding an illustration of the stereotype that blind people are pathetic and to be pitied, Participant C (M, 48) relates that on discovering his blindness, people often comment in the following manner: “Ag, shame, how do you handle it?” To be viewed as an object of pity alone is deeply demoralising and degrading.

A further aspect related to the issue of normality/abnormality is the perception that one is regarded as a spectacle or ‘freak show’. To some extent, a blind person loses his/her anonymity and privacy and becoming in some way a public figure, being conspicuous wherever he/she goes. Participant D3 (M, 26) relates the following:

I was walking in a shopping centre the other day, just walking up and down the aisles looking at this and that. I was told by my friend that lots of people stopped and stared, but no one actually came up to me to ask whether I would need some help. Either to help me buy something, or to help me out of the shop since I perhaps walked into the wrong shop. They treat it as abnormal, almost like a spectacle if a disabled person walks into the environment and either needs some help to a specific place, street, bus stop, shop or wherever. But, get some sighted people as your friends, then their eyes open and see that we are just as normal as they are. If normal is the right word.

This participant relates that on account of being regarded as not normal, others are reluctant to offer him assistance, even under circumstances where such assistance may well be needed.

Being thought of and treated as not normal (with all that this may imply to any given individual) is deeply upsetting and may impact negatively on the way blind people see themselves. This is illustrated by Participant C (M, 48), who regards sighted people as normal, suggesting that he thinks of himself as not normal. Being regarded by others as not normal may have been internalised and may now be part of how he sees himself. He says: “Most of the normal people as they think they are...” And: “There are normal people that are worse than disabled people.” Also: “People are

horrible and cruel and normally think normal so they only think of themselves and don't give any disabled person a chance easily.”

For the participants it is important to be like everyone else, to be seen as normal.

Participant D2 (M, 57) says:

Many sighted people would be surprised to find that I can add subtract, multiply, divide, and so on. That I can actually think, argue, write, dream, work out problems inside my head, operate a computer, build a computer, work on a car, drink a beer, tan a chop, smile, cry, hate, love and laugh, and all those interesting things that they also do...

This is an impassioned plea from the participant that he is in fact no different from others. He functions in every respect as others do; he is as normal as they are.

Not surprisingly, some participants go to great lengths to appear normal. They may do this by denying their disabilities and also consequently their needs. Participant M1 (F, 61) relates the following:

I was always self-conscious about my sight problem and tried to hide it from strangers with little tricks I developed to get me out of situations. As long as people did not see or know what my problem was.

Regarding such 'little tricks', she relates:

I had to leave school at the end of Standard Nine ... I became a sales lady at the Belfast, a big, grand store in Church Street. I did this work for one and a half years, having to memorise all the codes of the items and prizes of clothing, toys and babywear departments because at this time I could almost not read the big print at school any more.

This is an example of how the participant may have denied her disability; instead of telling her employer that she was unable to read the labels, she memorised their contents, a daunting undertaking for anyone. It was more important for her to be seen as normal, just like everyone else, than it was to receive the assistance needed to do her job without placing herself in such a stressful position.

4.2.5 The assumption that help is needed

All the participants mention that they have, at some time or another, been offered assistance by others. Most participants viewed such assistance (especially redundant assistance) with mixed feelings. By virtue of being part of the human race, we all from time to time need each other's help. Blind people therefore sometimes also require help and like anyone else are usually capable of asking for such help. However, when help is not needed but still offered (and often even 'forced' on the blind person), it is not received well. Participant D2 (M, 57) experienced the following:

Out of the goodness of their hearts, people always want to help me, especially when I don't need their help. But I always appreciate it, and often allow them to help me more than I actually needed their help. It makes them feel good, I think.

This illustrates the mixed feelings experienced by blind people regarding others' assistance. At the beginning of the extract, the participant related that he is always grateful for others' help, even when it is not really needed. In an attempt to show his appreciation, he often allows people to help more than what is actually required. This suggests that he is reluctant to eschew help; after all, just like anyone else, assistance may on occasion genuinely be required. At the same time, he is doubtful of the helpers' motives. He ends the extract by saying "it makes them feel good, I think". The use of the phrase "out of the goodness of their hearts" may contain elements of sarcasm. There is the suspicion that help is offered more for the good of the helper than for that of the person being helped.

Relating a similar experience of help given but not wanted or needed, Participant D3 (M, 26) says: "When I go out for a walk, with my guide dog, Nelly, people tend to grab me by the arm to help, when it is not needed at all!" Having unwanted assistance 'forced' on him (the helpers do not ask whether he is in need of help; they simply grab his arm) is experienced as intrusive. When referring to others' assistance, the participant expresses his sense of outrage by the use of the word 'grab'; the word also suggests that his personal space has been invaded.

This is what Participant J (M, 38) says:

They just 'think' disabled, so will offer to help with the simplest things, and will generally either talk rather loudly to you, or try asking people who know you better about your situation instead of asking you directly - and this sometimes while you're right there.

Some of the issues raised by this participant relate to the assumptions discussed above. He views others' assistance in terms of the fact that such assistance is linked to assumptions that blindness does not merely relate to not seeing but also equates to general incapacity. As suggested earlier, the blind person is offered assistance because, in addition to blindness, he/she is assumed to be unable to hear, speak or understand (mental incapacity) and is therefore treated as if he/she is invisible or not present.

Although there is the common response of politeness to assistance offered, and the need to be grateful, in general the participants responded negatively to others' assistance, especially redundant assistance. This may be because they are intuitively suspicious of others' motives; there may be an awareness that help is offered more for the good of the helper than for the good of the person receiving the help.

4.2.6 Worldview/belief system

The participants presented various responses to the assumptions reported above. These responses ranged from mild amusement, to irritation, frustration, indignation and even to extreme anger. The reason for the varying responses could in the first place be explained in terms of individual factors such as personality, intelligence, age, level of education, competence or skill. It could also be indicative of different levels of acceptance or resignation to a life of blindness. Despite the range of responses, it is clear that the participants are often offended by others' responses to their blindness.

A further aspect that may throw some light on the reason for the varied responses to living with blindness amidst a disablist society is a person's worldview or belief system. Inasmuch as the varied responses are indicative of different levels of

acceptance or resignation to a life of blindness, an individual's worldview and belief system can influence the way he/she views life and copes with its challenges. All the participants, except Participant J, specifically revealed that they are Christian. This seems to suggest that the Christian faith plays an important role in the participants' lives, and in how they experience and attempt to cope with living with blindness.

Participant D3 (M, 26) strongly proclaims his Christianity. In introducing himself, he calls himself "Christian true believer in Jesus Christ." Furthermore, he concludes with the following statement: "We are all people, I am not disabled, but I can do all things through Christ, my Lord, which strengthens me. Philippians 4:13." It is clear that this participant's faith plays a significant role in his life and assists him to cope with his blindness.

Participant C (M, 48) is studying towards becoming a pastor. This is how he starts his day:

Let me tell you some of my normal day. When I get up in the morning, that is about 5:00, then I'll start up my computer, connect on the Internet... After that I'll open my Bible software and start reading it and see what cross-references are there.

It is evident that this participant's faith is important to him and that he relies on some of its principles for guidance and support.

On the other hand, not being religious did not stop Participant J (M, 38) from making an external attribution for his loss. He was the only participant who did not say he or she is a Christian. In introducing himself, he states: "Religious affiliation: None/Atheist/Agnostic." Participant J ends all his contributions as follows: "...fate had broken his body, but not his spirit...." The implication of this is that what happened to him was not by Divine intervention but it was caused by fate.

4.3 The impact of others' attitudes on the emotional well-being of blind people

From what the participants have experienced in the course of living with blindness amidst a largely disablist society (see above), and from a reading of the literature (see Chapter 2), it would appear that interactions between blind people and the

sighted world are indeed informed by hidden assumptions as well as by psychic investments (a form of psychic 'pay-off' for the benefit of the sighted person) and that this influences the way sighted people treat blind people.

Furthermore, as per their experiences with the sighted world, blind people are intuitively aware that the responses of others are informed by such assumptions and imputations. By means of illustration, in interacting with the sighted world blind people relate that they often experience a certain strangeness or an uncomfortable silence around them or their blindness. Participant D1 (M, 70) male says: "If I could generalise, most people respond 'strange' to blind persons." He relates that he has also experienced the following when unaccompanied in a shop, for example: "I often get the impression that there is a slight delay before I am addressed when it becomes my turn in the queue."

Most of the participants revealed either explicitly or implicitly that being treated in this manner impacted negatively on their emotional and social well-being. A few issues relating to the ways in which blind people respond to this are raised here. Blind people respond in one of two ways. Firstly, some may internalise negative imputations; the undermining messages which blind people receive from the non-disabled world may become part of the way that blind people think and feel about themselves.

By means of illustrating this, Participant C (M, 48), in relating his life story, says that he has experienced that people do not want to get involved with him because "a disabled person is a risk, and they don't want to be held responsible". Regarding his career path, he mentions:

There are disabled people who don't work, not because they are lazy, but because they put blind or disabled people down. If you have to hear every day that you're handicapped and contribute nothing to society it will get stuck in your mind and eventually you will believe it. You will start acting like that and sit on your behind and the others will have to serve you.

He adds: "Remember all circumstances are very psychological in nature." By his own admission, others' treatment influenced his sense of self and self-worth.

Secondly, other disabled people may, as a form of resistance, define themselves in opposition to the negative assumptions and stereotyping ascribed to them. They may attempt to subvert such expectations by reversal and by making sure that their behaviour does not support any such traits. This forces them to live inauthentically, not being able to live out who they really are. Being prevented from articulating painful and difficult parts of personal experience, carries risk to self and identity. This may be one of the reasons why most of the participants did not directly express that they have experienced difficulty with for, example, some of the skills necessary for daily living. It is possible that some of them, in an attempt to define themselves in opposition to negative assumptions and stereotyping, would be unwilling to articulate (even to themselves), any behaviour or difficulty supporting or confirming such negative assumptions or stereotyping.

This kind of thinking may be seen as a form of denial. However, this kind of denial cannot be regarded as a form of psychopathology; instead, it is argued that denial of disability is totally rational given the situations disabled people find themselves in. Disabled people deny their disabilities for social, economic and emotional survival and they do so at considerable cost to their sense of self and their identities. This starts from an early age. Participant M1 (F, 60) says:

When I was young, I was always self-conscious about my sight problem and tried to hide it from strangers with little tricks I developed to get me out of situations. As long as people did not see or know what my problem was, at that stage I could still walk independently and did not look as if I had a sight problem. I was always complimented for my beautiful big brown eyes. I would walk into shops and browse around the shoes or whatever was the closest to the entrance until my eyes adjusted to the light in the shop. I also never told them why I could not read the price tags when I was confronted with the too familiar question. I just replied that my glasses are broken and I can't read without them, long stories.

Without being aware of it at the moment of doing it, the participant engaged in various forms of subterfuge in order to hide her 'problem' from others. Note the use of the following phrases: "little tricks I developed to get me out of situations" and "long stories". It is suggested that her denial of disability may serve twin purposes,

protecting the self as well as protecting others from the awkwardness around disability.

Most of these pressures to deny disability persist in adulthood. Also, many of the problems experienced by disabled adults are similar to those experienced by disabled children. When participant M1 (F, 60) became a sales lady (see extract above) she memorised all the codes and prices of items because she experienced difficulty in reading them. She says “I was scared of wasting their time, etc. ... like I sometimes used to do when I was younger.”

When the participant was a child she attempted to hide her poor sight from others by what she called “developing little tricks”. These included telling white lies concerning her sight or lack thereof. She may have done this because she was self-conscious about her disability and wanted to be regarded as normal or just like everyone else.

As an adult, she persisted in her attempts to hide her disability. She relates that she memorised all the codes and prices instead of asking for assistance. The reason she provides for this is that she was “scared of wasting their time”, like she did when she was a child. She is not aware of the fact that memorising the codes and prices amounts to employing one of the “little tricks” she developed as a child. She is, in effect, denying her disability.

One possible reason disabled people react in this way rather than being assertive about their disabilities may be to avoid the disapproval, rejection and adverse labelling of others, just as they did when they were children. However, disabled people seem to be caught between two opposing and equally inappropriate responses here: Either they are treated as totally incapable or they are treated as totally normal. Non-disabled people may respond with disbelief when disabled people attempt to convey the reality of their disabilities. By way of illustration, Participant J (M, 38) relates the following: “I have also had a couple of people think I am playing a form of practical joke, and pretending to be blind.”

Others’ disbelief conveys the message that disabled people are no different from others; this undermines the real experiences of disabled people. For some disabled

people, knowing how different they really are is problematic, making it easy to become confused and to have their confidence undermined, when others insist that such disabled people are just the same as them. Also, blind people are under constant social pressure to be as good as everyone else, possibly even better. This places the onus to achieve and succeed entirely on disabled people, with no suggestion that the world could adapt, or that their needs could or should be accommodated. The underlying message remains: 'Be superhuman and deny your disability'.

In this regard: Participant D3 (M, 26) claims: "I've got a cane, and a guide dog, and echo location that stand in for the loss of my sight. So, there's really nothing wrong with me". And: "...I choose to walk on my own, and generally try to do things on my own, being independent and self-directed." Although it is possible that this participant has come to full acceptance of his blindness and is managing admirably, it may also be possible that he has internalised others' insistence that disabled people are just the same as them and should consequently be superhuman and deny their disability. This may have now become part of who and what he is. For a blind person, the pressure to conduct one's life as if there is "really nothing wrong" could in some cases be intolerable.

4.4 The personal experience of living with blindness inclusive of accounts of loss

Disability is not primarily a form of social oppression, a mere socially imposed restriction, or a constructed category, neither is it simply impairment. It is, also, a personal experience, an experience inclusive of personal suffering and loss. The section below considers ways in which the participants shared some personal meanings concerning living with blindness and how the latter impacted on their lives. Inasmuch as any loss or personal suffering is articulated here, it is not the intention to ascribe loss and suffering to disabled people or to the participants, or to suggest in any way that these experiences belong to all disabled people.

In the course of relating their everyday experience of living with blindness, all the participants revealed, mostly indirectly but sometimes also directly, that they have experienced difficulties and hardship in various areas, some being common to all

and some unique. The participants expressed personal suffering amidst living in a disablist world, in the following areas: self-worth and self-esteem, physical integrity, social interaction, personal independence, everyday skills, the written word/technology, the visual perception of beauty and of the pleasurable.

4.4.1 Self-worth and self-esteem

In the course of living a life with blindness within a world that is essentially disablist, a person discovers and experiences many barriers: economic, environmental, social, physical; obstacles and difficulties of all kinds abound. Amidst such a life, an intellectual devaluation of self may take place. Moreover, the self is constantly placed under this burden which is joined by the weight of others' negative imputations, assumptions and associations, as well as a prohibition against articulating loss or suffering, the combined load of which may be hard to bear.

The concept of internalised oppression is helpful in this regard. Others' assumptions and negative responses concerning blindness and blind people may be internalised and may become part of who and what blind people become and how they think about themselves. Although only one of the participants (Participant D2) directly indicated that he experiences problems with self-worth and self-esteem, most of the participants have revealed through their contributions that this may be the case. Although skilful, clever people (some are in possession of excellent technical and academic competence), they reveal their low opinion of themselves and their skills.

Participant D2 (M, 57), whose qualifications include a BA in Social Sciences, a post-graduate qualification in Communication Studies and some "technical qualifications", says in his introduction: "the only status I have, is a marriage status; I am married." And, he ends his contribution with the following: "PS, Have I passed this test? I usually fail all kinds of tests like this dismally! HAHAHA!!" Both the above statements suggest that the participant suffers low self-esteem. The exclaimed "HAHAHA!!" is an ambivalent response; he attempts to make light of the matter, but the opposite is in fact the case. Furthermore, after providing a long list of his skills and competencies, he says:

To 'them', I was never capable of doing anything, so each and every thing I succeeded in doing, made them surprised. Even though I can do far more

things than most of them, they still treat me as someone who cannot really be as 'normal' as them.

He adds:

Prolonged exposure to such behavior has generated a strong feeling of low self-esteem in myself. Often I have felt it's better to act as useless as they expect I should be.

Clearly, having experienced such treatment over a sustained period has negatively affected the participant's sense of self and self-worth. This has almost certainly also impacted adversely on his emotional well-being.

Experiences of exclusion, marginalisation and rejection can be internalised and might lead to psychological responses like compliance, resistance, anger, withdrawal and despair. Some of what Participant C (M, 48) relates illustrates this. Participant C, who worked as computer skills trainer, experienced that there is a great stigma around being blind and feels excluded, rejected and possibly even marginalised. He relates being treated by sighted people in the following ways: "...when they find out you are blind, they recoil and communicate less and less with you." He feels others don't want to get involved and consequently avoid him. He says the reason is:

...they don't want to be responsible in case something happens to the blind or disabled person. Because as they say a disabled person is a risk, and they don't want to be held responsible.

Furthermore, Participant C has experienced the assumption that blind people cannot do anything for themselves and consequently do not work. This has led to feelings of anger and even a certain level of aggression aimed at sighted people. He says:

Well, let's be honest with each other, there are blind and disabled people who would rather do nothing for themselves, but what they forget is that there are normal people that are worse than disabled people. They would rather sit on their behinds and let other people look after them and they are too lazy to work.

He is conceding that certain blind people may succumb to laziness, but juxtaposes this with the less excusable and less understandable laziness of sighted people, who lack this obvious reason for not working.

Participant C goes on to articulate his grievance against the sighted world by accusing sighted people of being selfish, which he claims is their normal disposition. He alleges that they withhold opportunities from disabled people and even attempt to sabotage any opportunities that may be granted. He says:

I can also say that people are horrible and cruel and normally think normal so they only think of themselves and don't give any disabled person a chance easily and if it happens that they give you a chance then you have to give your everything and prove yourself. And, believe me, then there are people who watch you like a hawk to see if you make a mistake so they can make you look bad to the boss or owner... It makes me fed-up.

He therefore justifies the so-called laziness of blind people on the grounds of how sighted people unfairly treat them. He says:

Some blind people don't work, not because they are lazy, but rather because they get put down all their lives. If you have to hear every day that you're handicapped and contribute nothing to society it will get stuck in your mind and eventually you will believe it. You will start acting like that and sit on your behind and the others will have to serve you.

He adds: "Remember all circumstances are very psychological in nature." With this comment he may be conceding that his experience of the way others have viewed and treated him throughout the course of his life has had a negative impact on his sense of self and his emotional well-being. Internalising negative responses, assumptions and stereotypes concerning the ability, rejection and hardships of blind people may lead to all of these becoming a part of and defining who a blind person is. The identities 'different', 'not able' and 'not normal' might eventually be adopted.

4.4.2 Physical integrity/normality

The data revealed that, in living with blindness, some of the participants described experiences of being viewed as "not normal", as "a spectacle or a freak show" or as

“an extra-terrestrial being”. Some of them also related that they consequently experienced that others see and treat them in terms of “a risk”, “a responsibility” or “a threat”. As has been presented in the extracts above, as a result of their blindness, they have been ignored, recoiled from, stared at, and offered unnecessary assistance.

Living with blindness over many years can impact negatively on the emotional and social well-being of blind people. It takes its toll to be viewed by others as someone who does not conform to what is average in terms of appearance, function or behaviour; to be seen as other, alien; or as someone who does not belong and someone who is not normal.

It comes as no surprise, therefore, that the experience of living with blindness amidst an essentially disablist world may affect the way a person views his/her own body. The blind person may come to feel physically diminished, unattractive, not a whole person and even insecure about his/her very humanness. Consequently, feelings of being different from other people, of not being normal and of exclusion from the group may arise. Such feelings are not caused primarily by impairment, but are largely a response to the way others respond to difference.

None of the participants directly raised the topic of how they view their body, possibly because they were not asked the right questions, or perhaps because it was not significant for them. It may also be a topic that is uncomfortably closely linked to self and identity. In referring to sighted people as normal people, the participants imply that they themselves feel (or are) in some way different or not normal. It may therefore be too painful or harmful to self to even bring the issue to the level of self-awareness, let alone articulate it to others. Alternatively, it may mean that it was not significant for them.

4.4.3 Social interaction

Many people, whether blind or sighted, may for many reasons experience various kinds of social difficulties. It is therefore not blindness per se that lies at the root of any difficulties with social interaction experienced by blind people; rather, it is the way blindness is perceived and treated. This is borne out by what Participant C (M,

48) says: "When they find out you are blind, they recoil and communicate less and less with you." If others indeed behave as described in the extract above, it is no wonder that interaction between the blind and the sighted may be problematic. Experiencing that others recoil on account of one's blindness will more than likely inhibit the participant's future social interaction with sighted people.

The experience of blindness is not confined to the world of the blind person alone; rather, it is socially and interactionally constructed and thus has implications for both blind and sighted people. However, according to the participants, sighted people are generally uncomfortable around blindness and blind people. Social interaction is largely complicated by others' discomfort and this affects the way blind people are treated. By way of illustrating this, Participant D1 (M, 70) observed that: "Most people respond 'strange' to blind persons". This awkwardness or strangeness places strain on the interaction, causing a cycle of social difficulty; the sighted person's awkwardness leads to either avoiding or ignoring the blind person, or to defensive manoeuvres, such as offering redundant assistance. This in turn leads to the blind person either withdrawing or responding in some other way that is not conducive to further social interaction.

Given that blind people have to operate within the social arena amidst an essentially disablist world, blind people may in addition, experience social difficulties, inclusive of difficulties with spoken communication and ordinary listening. This does not usually apply to one-on-one communication, but rather to when interacting within a larger group. All the participants relate that they have experienced such difficulties including social uncertainties such as how loudly to speak, whether he/she is being addressed, where the other person is and whether his/her companion has left him/her. The inability to make eye-contact is also problematic.

Participant D2 (M, 57) says in this regard:

Most conversations between a few people tend to turn into confusion to me and I'm usually left out of it. As eye contact is so impossible to me, in conversations people tend to ignore my presence, and even while I'm happily talking to someone, or thinking I'm having a conversation with him/her, he/she would often suddenly turn his/her attention to someone else who has come

up... I prefer to communicate via telephone, radio or computer. Because, it's easier.

Participant M2 (F, 45) also relates that she finds that the inability to make eye-contact interferes with social interaction. She says: "Lack of eye contact sometimes leads to sighted people addressing a person next to me instead of me, even if I was the one who initiated the meeting." Prolonged experiences of this kind may lead to the blind person feeling socially inadequate. This may impact negatively on such a person's self-image and may lead to avoidance of certain social situations and activities and, eventually, may contribute to social isolation.

Although all the participants related some kind of social difficulty, they generally did not link such difficulties directly to self-image and emotional well-being. This may suggest that the participants do not regard social difficulties as impacting on their self-image. However, it is also possible that explicitly owning-up to such feelings may feel too dangerous to the self. Admitting to social inadequacy may imply conceding to not being fully socially acceptable.

Some participants adopted a proactive approach regarding social interaction.

Participant M1 (F, 60) says:

If we, as blind people, are not prepared to change our attitude towards life and speak up for ourselves, then society will never learn about blindness. We cannot help that we have a disability, but, we have to accept it first before we can change the way that the public sees that we are normal, but for our eye problem. It is up to us to change the perception that the world has about blindness and it starts at home.

She says the following about the social challenges blind people have to face:

Sometimes we get shoved onto a chair and forgotten about at work parties, church teas and functions, unless we open our mouths and ask the person who we are with, to please help us and in the correct way, but very gently or by just explaining the situation.

The participant feels that a blind person's social difficulties are in part in the hands of the blind person him/herself, and not entirely to be laid at the door of sighted society alone.

Participant A (M, unknown) concurs and says:

Disabled people can do a lot from their side to bridge the gap. After all, they are the ones who know best how to explain and inform people about the challenges they have to face every day.

This is a positive response to adversity; from the words of these participants, it may be deduced that it feels good to be doing something to help oneself.

4.4.4 Personal independence

Disabled people are under continued pressure from within and from without to be normal, to be as good as everyone else, possibly even better. This pressure also implies that to be normal means to be independent. Most of the participants raised some aspect regarding the issue of independence. Although there are some mixed feelings about the matter, most felt that it is necessary for blind people to be as independent as possible. For some of them being seen as independent is extremely important. To be seen as coping, being in charge of one's own affairs, one's own life suggests being normal, being like everyone else. Illustrating this, Participant D3 (M, 26) says:

Some blind people are being guided; others, like me, choose to walk on my own, and generally try to do things on my own, being independent, and self-directed.

However, most blind people come to realise that total independence is not possible and learn to accept help from others, resulting in a certain degree of dependence on others. Some participants experience difficulty in coming to terms with this.

Participant D3 goes on to say: "And I don't think blind people need relationships more than other people. I think that's nonsense. I don't want to depend on people."

It is clear that this participant has mixed feelings about independence, because notwithstanding his need for independence, he realises that blind people cannot

afford the luxury of eschewing sighted friends. On the topic of friends he says pragmatically:

I won't say you should only mingle with blind friends or peers. Yes, some sighted friends might think that you only use them to take you to the shops or to help you with stuff, but that's what friends are for? [You]...have friendships with people close by, and when you're stuck and you have to go somewhere, you have some options.

Along the same lines, Participant M1 (F, 60) remarks:

It is also very good to have friends from both sides. It can make things a bit easier on the circle because, and this is for practical reasons, your sighted friends might have transport and it can be good.

4.4.5 Everyday skills

It is more than likely that most blind people experience many repeated minor frustrations in the course of their daily lives and this may constantly remind them of the fact that they are blind. Typical frustrations include being unable to read the label on items, battling to pick up a small object from the floor, getting to the phone before it stops ringing and many more small inconveniences. All these many minor inconveniences can amount over time, to a major stress.

Although all of the participants must, at some time or another, have experienced at least some of these frequent inconveniences related to living with blindness, none of them mentioned it. Again as mentioned above, it is possible that the right questions were simply not asked in this regard. Although the impact of these inconveniences may differ from person to person, it is unlikely that at least some difficulty with certain aspects of daily living is not a part of the participants' experience. However, perhaps none of them has mentioned it because it may be important for the participants' self-esteem not to concede to having any difficulty in terms of the skills required for successful daily living. It is further suggested that it may be too painful for the participants to articulate any experience of loss and suffering in this area, for fear that they may be seen as not coping, not competent, not whole, not normal.

4.4.6 The written word/technology

Reading and writing are essential skills and thus, inasmuch as losing the 'ease' of reading and writing is applicable here, it is worth mentioning certain aspects pertaining to the topic. In addition, the impact of assistive devices on the lives of blind people is of interest.

All the participants use CMC on a daily basis. In order to participate in this research project, they all have had to use assistive technology for the blind. Communicating in an online environment avoids the prejudices that are often triggered by visible signs of disability. Some blind people may prefer this kind of communication. This is what Participant D2 (M, 57) says in this regard: "I prefer to communicate via telephone, radio or computer. Because, it's easier...".

In this sample, it was the male participants especially who expressed how empowering access to CMC had been for them. In telling me about his daily activities, the first thing that Participant J (M, 38) mentioned is that he 'lives' most of the day on his computer. He says that this is due to "being a software/web application developer/programmer". However, he says: "[I am]...also still webmaster for my bike club" and "I do communicate with quite a few fellow blindies via e-mail mailing lists, skype chats, etc., etc." He also referred me to his personal website should I need more information concerning his background.

Participant D2 (M, 57) is also technologically minded, and rather than deal with face-to-face communication, he prefers to communicate "via the telephone, radio or computer". In discussing his frustrations at not being appointed to a job (see Section 4.2.3), he said he is, amongst other things, able to: "...design and construct a computer" and that he is far more computer literate [Technical and Academic] than the people they do appoint". He is also well informed concerning the latest technology for the blind and he referred me to various websites for the blind. He says: "...So, now we have been working for some years on an open-source, FREE screen reader, called NVDA, which is fast becoming better than even Jaws!"

Participant C (M, 48) has used his computer skills and was previously employed as a software trainer for other blind people. Even though he is currently helping on a farm,

his computer still plays an important role in his life. He says that using his computer to download emails and connect to the Internet are the first things he does in the morning. He also said

After supper about 7:30, most people get in the bath and go to bed, except for me. I'll rather sit behind my computer, on the Internet, surfing, send emails, and so on, till about 11:00.

4.4.7 Visual appreciation of the pleasurable and of beauty

The study did not specifically set out to explore the following aspects; therefore, questions probing these areas were not asked. However, in discussing other areas, some of the participants unwittingly touch on them.

Clearly, blind people are unable to appreciate the visual component of what is perceived by sighted people as giving pleasure; this includes the sex object. None of the participants referred directly to this aspect of living with blindness. This does not necessarily mean that this aspect of life is not important to blind people, or that it is not felt as a loss; rather, it may suggest that the matter is not easily spoken about. Although no one mentioned this loss directly, when discussing whether a blind person ought to marry a sighted person, Participant D2 (M, 57) mentioned in passing that: "sometimes, I think, we tend to forget that we have a body at all".

An issue related to the loss of the visual perception of the sex object is also mentioned by Participant C (M, 48). He says: "I can imagine why some of your participants said that blinds must married blinds, in short,... jealousy, is the main factor in many blinds' lives." Participant C goes on to say that, in a 'mixed' marriage, the blind partner might feel insecure:

The most fights in mixed couples' married lives are that the blind accuses the sighted that he or she can see and he or she looks for other men or women. Jealousy, jealousy, jealousy...and there the marriage is over.

This suggests that the issue is at least as real in the lives of blind people as it is in the lives of anyone else. Furthermore, it suggests that a lack of sight can impact negatively on the lives of blind people as it results in the loss of the visual component of what is perceived by sighted people as giving pleasure.

With regard to visual beauty, being able to visually appreciate beauty is obviously no longer possible for blind people. The extent or depth of this loss depends on whether the person was born blind or lost their sight later in life, and also on the degree of personal appreciation for beauty. This aspect was not under investigation in the study and no participant referred to it. It can, however, be surmised that Participant C (M, 48) must at least be aware of this aspect of blindness having an impact on his life. He remarks:

Yes, if you want to marry a blind if you like, but it will be better for a blind to marry a sighted person. The reason why I've said that a blind must married a sighted person, is there is so many things that a sighted person can tells you about everything that's going on around you, tells you colours, faces of people, seennary [sic] of the fields and so on, but if both are blind, I think it can be a dull life. ... Well I am glad I married a sighted person ... but without a sighted partner, it will not be easy at all..."

4.5 Conclusion

Utilising verbatim extracts which captured the essence of the point being demonstrated, this chapter attempted to tell the story revealed by the analysis of the data. The results were presented in terms of two general areas which emerged out of the analysis. These are: others' responses to blindness in the form of assumptions, stereotypes and psychic investments and the personal experience of living with blindness, inclusive of accounts of loss and personal suffering.

The themes and sub-themes that emerged from the data provided the basis for concluding that the interactions between blind people and the sighted world are informed by hidden assumptions and that such assumptions influence the way sighted people treat blind people. Also, it seemed that such assumptions are largely unconscious and reflect underlying societal discourses regarding disability. In addition, it emerged that the attitudes of sighted people regarding blindness and blind people are permeated with psychic investments. The analysis of the data further indicated that living with blindness leads to various impacts on the social and emotional well-being of blind people.

The main findings of the result section can be summarised as follows: The dominant theme of the study was that in the course of living with blindness, the participants had all, in the way that they had been treated, experienced others' hidden assumptions concerning blindness and blind people. Amongst such hidden assumptions were assumptions of general inability or incapacity, including the assumption that the participants are invisible or not worthy of being addressed because they are perceived as being unable to hear, speak, reason, understand or think. As a result they are assumed to be always in need of assistance or only capable to do certain jobs.

An additional assumption experienced by the participants was that they are regarded as not normal and as such should be pitied. A further finding was that not only are interactions between blind people and the sighted world informed by hidden assumptions, psychic investments (a form of psychic pay-off for the benefit of the sighted person) also played a role. The participants responded to such treatment with mild amusement, irritation, frustration, indignation and even extreme anger.

Despite the range of responses, it was clear that the participants were often offended by others' responses to their blindness. In addition, most of the participants revealed either explicitly or implicitly that being treated in this manner impacted negatively on their emotional and social well-being.

It also came to light that disability is not merely a form of social oppression, a socially imposed restriction, a constructed category, neither is it simply impairment. It is also a personal experience, inclusive of personal suffering and loss. The analysis of the results revealed how the latter impacted in various areas and mostly negatively on the participants' lives.

In the next chapter, the analysis of the data will be taken a step further, shifting from description to interpretation. The results will be discussed in relation to the research question and will attempt to show how the findings relate to the theory and literature introduced in Chapter 2.

Chapter 5: Discussion

5.1 Introduction

In this chapter the analysis will be broadened, moving from a descriptive to an interpretative level. The results will be discussed in relation to the research question and will demonstrate how the findings relate to the theory and literature introduced in Chapter 2. The interpretation of the results will be presented in terms of the two broad general areas which emerged out of the analysis. These are: others' responses to blindness in the form of assumptions, stereotypes and psychic investments and the personal experience of living with blindness amidst a disablist society.

In this study, the meaning of the concept of disability was explored, focusing on the real experience of disability, in this case, what it meant for the nine participants to live with blindness amidst a disablist world. The analysis of the data collected revealed that the real experience of blindness does not equate to the sum of the effects of impairment alone; rather, it is socially and interactionally constructed, and thus has implications for both blind and sighted people. The overall argument was that interactions between blind people and the sighted world are largely informed by hidden assumptions and that such assumptions influence the way sighted people treat blind people. A further focus of the study was the impact that living with blindness amidst a largely disablist society has on the emotional and social lives of blind people.

5.2 Others' responses to blindness

The analysis of the results of the data brought to light that in the course of living with blindness, the participants had experienced that others' treatment of them had a decided impact (mostly negative) on their lives. Despite the fact that some of them are highly qualified and accomplished people, all the participants reported that they were frequently treated in terms of certain misconceptions regarding blindness and blind people. Chief of these was being treated by others as if blindness equals total inability or incapacity. The implication of this is that they were treated as if unable to do anything for themselves or for anyone else. All the participants also reported that they are aware of a related misconception, that is, that people habitually link certain

jobs or careers exclusively with blind people, largely because blind people are unthinkingly viewed as only able or capable of doing certain jobs.

Some of the participants also revealed that, in the course of living with blindness, they experienced being treated as if they were invisible or not worthy of being addressed directly because of being regarded as not able to hear, speak, think or reason for themselves. For at least one participant this transpired to be more than merely a question of inability as this participant has experienced being judged as mentally incapable. This participant was therefore seen as unable to respond in the usual or normal way, becoming invisible to others who consequently rather addressed the sighted companion, who was regarded as mentally capable and therefore visible.

Related to the idea of mental incapacity is the notion of normality versus abnormality. The linking of disability with abnormality is well developed in the literature (French, 1993b; Marks, 2001; Morris, 1991; Watermeyer, 2006; 2009). According to Morris (1991), disabled people are regularly perceived and treated as if they were alien, not human, not normal, and as if they do not belong. Watermeyer (2006; 2009) observes that disabled people are seldom viewed as or treated as ordinary, normal people simply going about life's normal business. Consequently, French (1993b) mentions that right from when they are young and continuing into adulthood, blind people often attempt to deny their disability in order to appear normal amongst others. This is at considerable cost to self.

The analysis also revealed that it was a common occurrence for the participants to be viewed and treated by others as if they are not normal. Some have even experienced not being seen or treated as normal by those who know them well, including their own families. Flowing from the assumption that blind people are not normal, the participants also reported that in the course of their everyday lives, they had experienced being treated as if they are not ordinary people going about their ordinary business. In this regard, some of the participants reported that they were sometimes unthinkingly treated as tragic figures in need only of pity, and on other occasions, they were undeservedly treated as super-heroes.

Thus, the way the participants were treated was not based on the real situation; that is, they were not treated in terms of the sighted person's actual, real knowledge of the blind person or his/her life. Consequently, it came to light from the analysis that the participants experienced this treatment by the sighted world as demeaning and insulting; this was deeply upsetting and therefore potentially capable of impacting negatively on the way they see themselves. Via the mechanisms of internalised oppression, a concept that is well represented in the literature (Marks, 2001; Morris, 1991; Watermeyer, 2009), such undermining responses from the sighted world may have become part of the way some participants think and feel about themselves.

According to Marks (2001), the concept of internalised oppression operates when others' assumptions and negative responses concerning blindness and blind people are internalised and as such become part of who blind people become and how they perceive themselves. She further holds that blind people may consciously (or more likely unconsciously) experience exclusion, marginalisation and rejection and that these may be internalised. As borne out by the analysis of the data, this may lead to anger, withdrawal, compliance, resistance and/or despair. As this process is mostly unconscious, the blind person may be unaware of it. This is because some experiences are so painful that they are repressed from conscious awareness, although they continue to affect self-esteem and to influence thoughts and behaviour (Marks, 2001).

It is evident from the data that more than one of the participants exhibited behaviour that may indicate withdrawal. One of the participants mentioned that he feels left out when interacting with sighted people on a face-to-face basis and that he finds communication via the computer easier. This could amount to social withdrawal. Another participant related that he is regularly cheated by being given the wrong change in shops. Instead of confronting the shopkeeper, he remains silent but never returns to such a shop. Thus, rather than confronting the problem, he withdraws.

At least one of the participants exhibited a large measure of anger specifically aimed at sighted people. Furthermore, more than one of the participants indirectly expressed despair, specifically in relation to their career. One of the participants

directly related that being undervalued in the work place has led to feelings of despondence.

Some of the participants revealed a level of compliance with others' assumptions of them. In this regard, a participant mentioned that there is nothing wrong with him and that he is just like everyone else. The assumption here may be that blind people must deny their disability, be a super-hero and be no different from others. Another participant mentioned that he is often tempted to be just as useless as others assume him to be.

According to Mason (1992), internalised oppression cannot be seen as the cause, but rather as the result of disabled people's mistreatment. She holds that this oppression would, however, not exist without the real external oppression that forms the social climate in which disabled people have to live their lives. She further observes that once oppression has been internalised, it may impact negatively on disabled people in terms of negative self-image and low expectations throughout their lives (Mason, 1992, in Marks, 2001).

It was clear from the analysis of the data that most of the participants revealed (mostly indirectly) that others' negative attitudes and treatment of blindness had an adverse effect on their emotional well-being. At least one of the participants directly mentioned that others' treatment of him has led to low self-esteem.

5.2.1 Responses to others' treatment

The analysis further revealed that each of the participants responded to others' treatment in his or her own way. Responses ranged from mild amusement, to irritation, frustration, indignation and even to extreme anger. There may be many reasons for the various responses; those who are gainfully employed, financially secure, happily married or in possession of a strong support system may cope better with such treatment. Personal factors like personality, age, gender, physical appearance, education, level of competence or skill also may play a role. In addition, the participants' individual approach to living with blindness may be an important factor. Those participants who are comfortable with their own bodies, in particular their blindness, may find it easier to manage living with impairment amidst a disablist

world. A certain level of acceptance of one's blindness may be helpful here. It is also possible that some blind people may respond to others' treatment with indifference.

It came to light from the analysis that there existed a certain ambivalence in the way some participants responded to others' treatment; for example, in some cases they simultaneously expressed both amusement or mirth, and indignation or contempt. This may be because blind people, living in an essentially disablist world as they do, are placed in a position where they are reluctant to articulate (even to themselves) any impairment-related behaviour. As a result, they employ humour or make light of the situation, in essence denying their disability. The reason for this may be because they feel a need to safeguard sighted people from any embarrassment or anxiety regarding blindness.

This point is also made in the literature by French (1993b) when she argues that blind people frequently have to deny their disability for the above reason. A further reason is that blind people may also respond in such a way, making light of or denying their disability, for fear of being labelled or identified in terms of impairment-related behaviour (Watermeyer, 2009). However, the real response may be feeling hurt, insulted, offended or angry, so blind people may simultaneously react with contempt or sarcasm, giving vent to feelings that are essentially negative.

It furthermore emerged from the analysis that living with blindness and at the same time constantly being exposed to and treated in terms of others' mostly incorrect assumptions concerning blindness and blind people, impacted in various ways on the emotional and social lives of the participants. Some appeared not to be unduly negatively affected by others' treatment; some exhibited a stoic acceptance. Some withdrew socially, some felt rejected and excluded and consequently despondent, indignant and angry.

Again, the reason for the varying reactions may lie in personal and situational factors. It could also be indicative of different levels of acceptance and resignation to a life of blindness. Some may have fully accepted their blindness, leading to being more comfortable or at ease with their blindness and coping better with life amidst a largely disablist society. Others again may be less hardy, spending their lives

beleaguered by feelings of deprivation and loss, reacting with bitterness and mostly impotent rage.

5.3 Belief system/religion/locus of control

A participant's world view or religion may be a factor in determining how he/she responds to living with blindness in general and with others' treatment in particular. From the literature (Neill, 2006), the conclusion can loosely be drawn that when blind people strongly believe that their behaviour is informed and guided by an external factor such as God or fate, they may perceive their actions as contingent on events outside their personal control.

The implication of this is that for those who believe in a God, in this case most of the participants, the underlying belief may be that God is in control of their lives. Suffering and adversity may be seen as in His plan and ultimately for the sufferer's good. Furthermore, there may be a perception that God provides the believer with strength and help.

In the literature (Neill, 2006), it is suggested that when people see their lives as guided by an outside force such as God, there may be a tendency not to view the ultimate responsibility for their well-being as resting with themselves. Guidance, support and solace are sought outside the person. Furthermore, when things go wrong, there is always something or someone else to blame (Neill, 2006). As the matter is in God's hands, there may also be a subtle tendency towards acceptance of one's lot, possibly without much of a desire or attempt to do anything about it for oneself.

Those who are not religious, but who blame fate for their troubles, would not look to God for help or strength. Nevertheless, what has happened to them, their blindness, is seen as out of their control. They are at the mercy of fate. One of the participants who is not religious, concluded all his email contributions in the following manner: "fate has broken his body but not his spirit" and he would therefore not look to God for help or strength. Nevertheless, he may experience what has happened to him, his blindness and partial loss of hearing, as out of his control. In this participant's

case, there is no higher force like God to turn to for guidance and solace and he may therefore experience feelings of unfocused anger.

5.4 Hidden assumptions

From a reading of the literature, it appeared that the real experience of disability is not the result of impairment alone, but is also socially and interactionally constructed (Hughes, 2002; Marks, 2001; Thomas, 2002); this therefore has implications for both disabled and non-disabled people. However, as most people have had no personal experience of blindness or blind people, they are generally unaware and therefore largely ignorant of precisely what blindness, or living with blindness, may entail. This gap is filled by certain assumptions and associations regarding blindness which inform the way blind people are viewed and treated.

The literature as well as an analysis of the results revealed that any such assumptions and associations harboured by sighted people are therefore not logically a reflection of the real situation and can only have originated within sighted people (Watermeyer, 2006). Furthermore, it emerged from the literature that almost all interactions between blind people and the sighted world are informed by such assumptions (Morris, 1991; Watermeyer, 2006; 2009). In addition, the analysis of the results showed that the participants experienced being treated by others in terms of certain assumptions regarding blindness.

In the literature these assumptions are referred to as hidden because they are for the most part unconscious; sighted people are not aware of them, yet they influence the way sighted people treat blind people (Morris, 1991; Watermeyer, 2006). For this reason, it made no sense to ask sighted people directly about such assumptions. In this study, the investigation of the real experience of blindness therefore took place from the vantage point of the nine blind participants via their accounts of the way others treat them.

Now that the existence and effect of such assumptions have been firmly established by the literature as well as by an analysis of the data, it is useful to explore their origin and nature. The results section has engaged with the manifest level of the data. However, it is also important to go beyond the participants' words and to

explore the latent content of the data. To this end, in line with the literature, it is argued that these assumptions have their origin in certain societal discourses (Marks, 2001). Such societal discourses provide a basic framework for supporting and maintaining ideas concerning disability, underpinning the concept and influencing the way people understand and treat disability and disabled people (Marks, 2001).

One of these societal discourses is called the medical model of disability and, even today, this approach influences the way people view and treat disability. The nature and workings of the medical model are well documented in the literature (Barnes et al., 2002; Marks, 2001). Disability is viewed as the result of impairment, as an individual limitation, or as a personal problem, and not a societal issue (Marks, 2001; Oliver, 1990).

Most of the participants mentioned that they have experienced being viewed and treated in terms of assumptions underpinned by this model. For example, one of the participants related that upon encountering strangers, he has experienced that “they just ‘think’ disabled...”. Thereafter, any further interaction is not based on who such a blind person actually is, but rather on who such a blind person is assumed to be. Consequently, the participants reported that they have been avoided, ignored, recoiled from, and offered redundant assistance.

Further implications of this model are that disability is viewed as a medical problem; disabled people are made the responsibility of the medical profession and are placed in the sick role (Kaplan, 1999). In addition, disabled people are linked with tragedy, loss, bereavement and rehabilitation (Watermeyer, 2009). The underlying perception of this is that disabled people are not acceptable as they are; they need to be healed, or rehabilitated (French, 1993b; Morris, 1991). The implication for blind people is that, as a result of this societal discourse, they may unthinkingly be linked exclusively to impairment, assumed to be tragic figures always in need of pity and assistance, the very personification of loss and suffering.

As mentioned above, the workings of this medical discourse have been reflected in the participants’ experiences. All the participants have, in the course of living with

blindness, experienced the effects of such societal assumptions and associations. Some have explicitly reported on being treated in terms of certain assumptions and others have done so implicitly. Consequently, as demonstrated by the data as well as the literature, the participants, irrespective of who or what they are, or of their talents or capabilities, frequently experienced that they were perceived and treated as if incapable of anything and consequently always in need of assistance. They experienced being viewed and treated as not normal and furthermore not functioning in an everyday manner. Instead they experienced that they were perceived and treated as alien and not belonging, as either tragic figures, or as super-heroes.

However, not only do such individualising medical constructions of the concept continue to inform the understanding and treatment of disability, certain other societal discourses regarding the concept also play a role. The medical model has been challenged and transformed by a new political discourse in the form of the social model of disability (Barnes et al., 2002; Hughes, 2002; Marks, 2001; Shakespeare, 1996). This represents a new social approach to disability, where disability is no longer primarily to be found in the individual and his/her impairment; instead, people are seen to be disabled by social and environmental barriers (Marks, 2001).

The implication of the latter statement is that disability is seen as socially created and could thus potentially be solved simply by adjusting the social and physical environment to ensure that the needs and rights of people with impairments are met. This would include providing text-to-voice devices, more bleeper crossings or more electric wheelchairs, wider doorways and more ramps and lifts (French, 1993a). Clearly, another less dominant societal discourse, that is, one of simply adjusting the social and physical environment and then assuming that the needs and rights of disabled people are thereby met, is afoot. This issue was not addressed by the present study and may make for interesting inquiry for future research.

5.5 Psychic investments

Apart from others' attitudes being informed by hidden assumptions, interaction with the sighted world is complicated further by a certain awkwardness or discomfort around blindness or blind people; this is not only due to a mere lack of awareness or

ignorance. An analysis of the data tells the same tale and is supported by the literature. Some of the participants have mentioned that they have experienced a certain strangeness in the way others relate to them. One of the participants related that he has experienced an odd silence when first encountered by others.

In this regard, the literature confirmed that there is often an uncomfortable silence around disability and disabled people, affecting the way such people are viewed and consequently treated. This is accounted for in terms of non-disabled people's attitudes to disability being seen to be imbued with psychic investments (Marks, 2001).

In the literature (Marks, 2001; Murphy, 1995; Shakespeare, 1994; Watermeyer, 2006), this is explained by means of some insights of psycho-analysis. It is suggested that via Freud's model of the psyche, troublesome parts of being human are kept unconscious and in place by defence mechanisms like repression and denial. The parts of the self which are unacceptable are split off and projected onto disabled people, who have come to symbolise what is damaged, imperfect, undesirable, shameful and unwanted within humanity.

It emerged from an analysis of the data that, within the social arena, encounters with the sighted are usually accompanied by a certain awkwardness or strangeness. According to the literature, this is accompanied by a level of anxiety which is viewed as a defensive response to troublesome parts of the sighted person's own experience which another's blindness evokes. This may result in feelings of revulsion on the part of the sighted person which may lead to the sighted person simply avoiding the blind person (Marks, 2001; Watermeyer, 2006).

This was borne out by the data; the participants related that sighted people often avoided or ignored them on account of their blindness. One participant even reported that upon discovering his blindness, sighted people actually recoiled from him and stopped altogether from communicating with him. Further, the analysis of the data showed that such feelings of revulsion may be hidden by reactions of pity, giving rise to the urge to offer assistance (often unwanted). This is supported by the literature (Marks, 2001; Watermeyer, 2006).

It is in the area of assistance offered in particular, that the above-mentioned point is illustrated best. It is commonplace for everyone, blind people included, to need each other's help from time to time; consequently, in the course of life, assistance is offered and may be either accepted or rejected. The analysis of the data demonstrated that most blind people have been offered assistance; however, the assistance has usually been for activities or actions that they are perfectly capable of doing for themselves, thus such assistance is redundant.

It also appeared from the literature that it is commonplace for sighted people to decide that certain tasks, which the blind person can perform quite adequately, are beyond such a blind person, whilst at the same time not offering any help with what the blind person actually needs help with (French, 1993b). For example, as came to fore from the analysis of the data, others may 'grab' a blind stranger's arm to 'assist' while such a blind person is walking with a guide dog and managing to get around adequately on his/her own.

On the other hand, often within the social context, when a blind person needs to receive clear social signals from others, such others are uncomfortable around blindness and as a result may avoid or ignore the blind person. As a result of this awkwardness regarding blindness, the participants reported that they have experienced being over-looked, being recoiled from, being deserted in mid-sentence, not being taken seriously, being stared at, or simply being ignored.

It is no surprise, therefore, that blind people generally view others' assistance with mixed feelings. On the one hand, it would be unrealistic and impractical never to except others' assistance. No one can afford such a luxury. On the other hand, blind people are intuitively aware that the kind of help discussed here carries undertones of psychic pay-offs; that is, it is imbued with psychic investments (unacceptable or difficult feelings have been linked to and then projected onto blind people and thus in this way disowned) (Marks, 2001).

The analysis of the data, however, showed that the participants generally felt that others' help, even if redundant, ought to be accepted and appreciated. This is usually not because it is particularly helpful to the blind person, but rather because

the participants are aware of the fact that it makes the other (the sighted person) feel good. The implication of this is that blind people often accept redundant help in order to facilitate the other, the sighted person. On the other hand, the help offered by the sighted person may 'simply' be an expression of empathy and altruism. These dynamics can be understood by briefly investigating the psychic mechanism underpinning such offers of assistance.

According to Freudian theory, the defence of reaction formation is in operation here. This defence involves going to the opposite extreme to obscure or counter unacceptable feelings. Feelings of revulsion towards the blind person are accompanied by an impulse to remove from sight the object causing the reaction. At the same time, the sighted person experiences guilt and anxiety, because such a desire is unacceptable in our society. Seeking to free him- or herself of it, the initial feeling of revulsion is turned into the acceptable feeling of pity, which results in help being offered to the blind person (Braverman, 1951; Marks, 2001). According to this view, the pity that is felt is a response to the inner needs of the sighted person and satisfies the giver of help (the sighted person) rather than the receiver of help (the blind person). Further, the blind person is expected to display gratitude and generally does so (Braverman, 1951).

A further related issue that emerged from the data analysis is the situation where the participants were reluctant to ask for or accept help when help was actually needed. In essence, the disabled person feels placed in a position where he/she is denying his/her disability for the others' benefit. According to the literature, this happens when, simply as a result of their presence, blind people provoke anxiety and embarrassment in others. This leads to blind people denying their disability in order to protect sighted people's feelings and to allay such sighted people's anxieties, that is, to comfort, console or reassure others (French, 1993b). This is at great cost to themselves, because in order to safeguard the feelings of others, blind people are not only compelled to deny their disabilities, but in effect, also their real needs.

In the analysis of the results, for example, one of the participants related that he needed assistance with shopping, but did not ask for help because he sensed that his very presence provoked anxiety and embarrassment in others. Another

participant reported that, in order not to waste her employer's time when working as a shop assistant, she resorted to memorising the codes and prices on labels rather than to owning up to her poor sight. She resorted to such extreme measures, in the process denying her disability and forgoing much needed assistance, possibly to safeguard sighted people's feelings and to retain her job.

The literature further revealed that it is not unusual for blind people to endure boredom, discomfort or even distress, whilst at the same time automatically offering reassuring phrases such as 'I'm all right' or 'Don't worry about me' (French, 1993b). To illustrate this, a blind person may for example, offer to sit and wait somewhere out of the way or to do without a much-needed item or service in order to forestall possible awkwardness or to safeguard the sighted person from trouble or embarrassment.

However, none of the participants referred to having experienced such situations. This need not indicate that they have not experienced these situations, but may suggest that the participants did not share such deeply personal experiences with the researcher, partly because of constraints in the methodology. Individual interviews over a longer period of time may have facilitated a better rapport with the participants, encouraging them to share more personal, even painful, experiences. This may have led to a better exploration of the real experience of disability. Using a different methodology, an exploration of such situations may make for interesting future research.

Before moving on to the next section, it may be useful here to present a short summary of what has already been explored in this chapter and what will still be discussed. The interpretation of the data is presented in terms of two broad general areas which emerged out of the analysis. These are: others' responses to blindness in the form of assumptions, stereotypes and psychic investments, as well as how the participants responded to others' treatment (see the section above) and the personal experience of living with blindness amidst a disablist society. All the participants related, directly or indirectly, that the real experience of actually living with impairment has had an impact on their lives. This will be discussed in the section that follows.

5.6 The personal experience of living with blindness

The analysis of the data revealed that disability is essentially a personal experience, inclusive of loss and suffering. The fact that the participants did not directly use words such as loss or suffering to describe their experience of living with blindness may suggest that they do not necessarily understand their world in terms of these. However, all the participants related that their real experience, which is actually living with impairment, has had an impact on their lives. It was further clear from the data that, in living with impairment, all the participants have experienced difficulties and hardship in various areas, some common to all and some unique, and that this may have had a negative impact on their emotional and social well-being.

This is also reflected in the literature (Marks, 2001; Shakespeare, 1996; Thomas, 2002), where disability is revealed as a complex concept, a personal experience of impairment, but also a socially imposed restriction, a form of social oppression and a constructed category.

It is further apparent from the literature (Hughes, 2002; Thomas, 2002) that the experience of the body, the real experience of living with impairment, has not been recognised or opened for interrogation. Thus, in line with a reading of the literature as well as from the analysis of the data, it is evident that the personal experience of living with impairment is real, and as such, ought to be acknowledged and encompassed within the concept of disability. However, such an undertaking implies employing caution and sensitivity; it should in no way be seen as an attempt to collude with individualising medical approaches, or to pathologise disability and disabled people by characterising them as inherently damaged, rather than acknowledging that they may be the victims of a form of social injustice (Watermeyer, 2013).

Further, the idea is not to ascribe loss to blind people or to construct blind people as powerless. It is also not the writer's intention to suggest that the attitudes of sighted people are in any way a conscious attempt to demean, devalue or exclude blind people. As assumptions and associations concerning blindness and blind people operate largely on an unconscious level, sighted people are not aware of the fact that their thinking may be informed by these assumptions. Furthermore, it is not so

much the attitudes and responses of individual people at issue; rather, it is societal discourses that underpin the concept and that affect the way disabled people, including blind people, are perceived and treated.

5.6.1 The emotional and social well-being of blind people

It is not blindness (impairment) alone that impacts negatively on the emotional well-being of blind people; it is also the attitudes and actions of others in relation to blind people that constitute the real experience of blindness. Thus, the experience is not limited to the world of the blind person alone; it is interactionally constructed and the perceptions and actions of others play a role in this.

An analysis of the data showed that living with blindness amidst a largely disablist society may have negatively affected the participants' emotional and social lives. The participants have expressed mainly indirectly, but also sometimes directly, personal suffering in various areas of their lives.

5.6.1.1 Self-concept and self-esteem

In the areas of self-concept and self-esteem, a careful reading of what lies beneath the words of the participants suggested that most of them may have experienced that living with blindness amidst a world that is essentially disablist may have negatively influenced the way that they think and feel about themselves.

According to the literature, self-concept is the perception that a person has of him- or herself; each individual's self-image is a mix of different aspects including physical characteristics, personality traits, personal abilities and social roles (Pastorino & Doyle-Portillo, 2013). Regarding self-concept and the way the participants think about themselves, it appeared from the analysis that this was influenced by the physical, social and even economic obstacles and barriers related to living with blindness which the participants frequently encountered and experienced.

Physical obstacles include lack of or difficulty with mobility, transport difficulties, inability to get from A to B without relying on others, not being able to read signs, labels, instructions and many others. Social difficulties include being ignored, avoided or even rejected by others on account of one's blindness. Furthermore,

several participants directly expressed frustration with the workplace, either for not being able to get a job or being under-valued. Clearly, this has economic implications for such participants. It may be deduced from this that these experiences resulted in the participants having a constant awareness of being blind, of being different, which was relentlessly reinforced by others. According to the literature, over many years, this may have the effect of bringing about an intellectual devaluation of self (Carroll, 1961).

The literature further draws a distinction between self-concept and self-esteem. The latter refers to a person's general attitude towards him- or herself, that is, how such a person evaluates him- or herself (Pastorino & Doyle-Portillo, 2013). Although only one of the participants revealed directly that he had experienced problems with self-worth and self-esteem, a careful reading of what is beneath the surface of their words indicates that this was indeed the case for most of the participants. All of them related that the way others perceived and treated them had some impact on their lives. Even though not all of them expressly said so, being regarded and treated as incapable of anything or not normal, when the opposite is in fact true, could eventually affect the way one sees oneself.

One of the participants gave voice to this when he related that, notwithstanding being highly skilled and well qualified, and able to do as much and even more than others, he nevertheless did not ever receive the recognition he felt he rightfully deserved. He experienced it as unjust and unfair that less skilled and qualified sighted people were appointed over him. Such discrimination on the grounds of his blindness left him feeling despondent and discouraged. By his own admission, this affected his self-worth and self-esteem.

It is mentioned in the theory that how people compare themselves to others and how others in turn respond to them, can impact on a person's self-esteem. When people compare themselves to others and find themselves lacking, it can have a negative impact on such a person's self-esteem (Pastorino & Doyle-Portillo, 2013). Similarly, as was the case with some of the participants, when the comparison reveals that they are at least the same or in fact better than others and yet they find themselves being treated as if they are lacking, the effect on self-esteem is obvious.

Yet another participant expressed a high level of anger towards sighted people on account of how he perceived that they have treated blind people in general, and by implication, him in particular. He related that he experienced that sighted people recoiled from him on account of his blindness, avoided getting involved with him because he poses too much of a risk as a disabled person and by implication, denied him job opportunities. Even when such opportunities came his way, he claimed that he experienced that others tended not to encourage him but rather to hinder him. From his story, it was evident that in living with blindness, he has experienced many difficulties in his personal and vocational life. Adding the weight of others' negative imputations, assumptions and associations to this may have placed a heavy burden on his sense of self and his self-worth.

It is also possible that he may have internalised others' assumptions and negative responses concerning blindness and blind people such that this may have become part of his identity. Internalised oppression is also mentioned in the literature. As discussed previously, blind people may consciously or unconsciously internalise experiences where they are excluded, marginalised or rejected. This internalisation may lead to compliance, resistance, anger, withdrawal and despair. These painful experiences may be repressed from conscious awareness and be outside conscious awareness, although they continue to impact on self-esteem (Marks, 2001).

Another aspect of living with blindness linked to self-concept and self-esteem is that of physical integrity and wholeness. This issue is linked to body image and the way people view difference, and plays an important part in how blind people are viewed and treated. The analysis of the data revealed that the participants have experienced that others generally viewed them as different on account of biological difference (blindness), and consequently as not normal. The participants further related that this influenced the way others responded to and treated them. The participants also related that they experienced being viewed and treated in such a manner as unacceptable and upsetting.

To offer some explanation for why people are inclined to view blind people as different or not normal, the literature depends on some psychoanalytical insights. Painful or difficult feelings evoked by another's blindness are managed by means of

defence mechanisms, strategies to deflect, disguise or re-order parts of self which people cannot bear to know (Marks, 2001; Watermeyer, 2006). The idea that people can be categorised as either normal or abnormal is such a defence mechanism and reflects a form of splitting. This is a primitive form of black-and-white thinking which implies that the world can be divided clearly into a set of binary opposites, making no provision for grey areas (Marks, 2001; Watermeyer, 2006). As the analysis has shown, most of the participants referred to sighted people as normal, and reported that they themselves had experienced that others view them as not normal.

To complicate matters further, it appeared from the literature that disabled and non-disabled alike find difference problematic. It is not only non-disabled people who might, as a result of unconscious investments, respond irrationally to disability. Often blind people struggle with their own difference and may feel rejection, pity, and even revulsion for themselves. They too have connected ideas and images of disabled people to unwanted parts of themselves. Also, like everyone else, their conscious minds deploy defence mechanisms to manage the threat of painful or difficult feelings encroaching from the unconscious (Marks, 2001; Watermeyer, 2006). Because of the nature of this kind of response, this is clearly not an issue that the participants would be able to report on within the constraints of the present study. The manner in which disabled people themselves respond to difference could make for an interesting exploration in future research, via a different methodology.

In addition, not only do blind people have to cope with others' as well as their own assumptions regarding difference and normality, it also transpired from the theory that body image is an important part of a person's self-concept. Thus, being suddenly blinded, or living with blindness over a long period, may deal a devastating blow to body image and consequently also to self-concept. This may result in a blind person experiencing a loss of physical integrity, a loss of wholeness, even to insecurity about one's very humanness. Consequently, feelings of not being physically competent, able, adequate or attractive may arise. Further, as discussed above, feelings of being different from other people, of not being normal, and even of exclusion from the group may also be present (Carroll, 1961).

From an analysis of the data, it was clear that being regarded as different and not normal was an experience common to most of the participants and that being regarded in this way had a negative effect on the participants' emotional and social well-being. None, however, reported that they themselves experienced feelings of being different from others, but some did refer to others as normal, suggesting that they view themselves as not normal. This latter may be accounted for in terms of internalised oppression.

It was evident from the analysis that some participants have experienced feeling rejected and excluded. In this regard, the participants reported that they have, on account of their blindness, been recoiled from, avoided, ignored and overlooked within the workplace. Some of the participants also reported that they have experienced being viewed as an extra-terrestrial being, as a spectacle or freak show, as alien. This seems to imply that others viewed them unthinkingly as not fully human, as not belonging. Such deeply undermining messages from the sighted world may well have been internalised by some of the participants, becoming part of how they view themselves. Even were this not the case, experiencing over a long time being regarded by others in such a manner, could well leave its mark on self-concept and self-worth.

Regarding blindness and body image, with the exception of one participant who made a passing reference to the fact that he has almost forgotten his body (in relation to marriage), none of the participants directly mentioned that their blindness has had an effect on the way they view their bodies. Nor did any of them mention that they have experienced feelings of not being physically competent, able, adequate, or attractive. According to the literature, blind people may relate negatively to their own difference (Watermeyer, 2006). In an attempt to keep such feelings unconscious, the consequent repressing of such painful feelings may lead to neglecting aspects of the body and any reflection on body image and blindness.

On the other hand, the participants may well have experienced some or even all of these in the course of living with blindness amidst what is today in essence, a narcissistic society preoccupied with bodily perfection. It is suggested that the participants did not refer to such experiences partly because body image, blindness

and self-esteem are too closely linked. They may have felt that it was not safe in terms of identity and self-worth to acknowledge such feelings, even to themselves. Furthermore, the methodology used in this study may not have encouraged the participants to reveal such intimate information. It is possible that the right questions were simply not asked.

5.6.1.2 Social interaction

Social difficulties are not uniquely confined to blind people; they are a problem common to all. In addition, not all blind people experience social difficulties. It is therefore not blindness per se that lies at the root of any difficulties with social interaction experienced by blind people; after all, the real experience of blindness is at least in part interactionally constructed. Therefore, the way blindness is perceived and treated by others plays a decisive role.

The literature mentions that others experience a certain discomfort or awkwardness when encountering blind people (Marks, 2001). The analysis of the data indicated that the participants have experienced that this discomfort or awkwardness around blind people complicated their social interaction. One of the participants mentioned a certain strangeness or odd silence that follows the initial discovery of his blindness. Another participant reported that on discovering that he was blind, others actually recoiled and terminated all communication with him. Some related that they were ignored or avoided on account of their blindness. All the participants reported that, as a first response to their blindness, others sometimes apparently automatically and unthinkingly offered them redundant assistance.

In the literature, this discomfort is understood in terms of the psychoanalytical model. It is argued that when a sighted person encounters a blind stranger within the social arena, the experience is accompanied by anxiety. This anxiety is viewed as a defensive response to troublesome parts of the sighted person's own experience which a confrontation with another's blindness evokes (Marks, 2001). This results in the sighted person either ignoring or avoiding the blind person, or alternatively, offering unwanted assistance (Marks, 2001; Watermeyer, 2006).

In practice, the effect of this is that in the social arena, the discomfort experienced by sighted people regarding blindness and blind people effectively amounts to an invisible barrier being erected between the blind and the sighted which may be hard to breach. It has the further effect of causing a cycle of awkwardness, avoidance and defensive manoeuvres (such as offering redundant assistance), which lead to withdrawal, or other responses not conducive to further social interaction. Eventually, these lead to the blind person experiencing a loss of social adequacy which may contribute to social exclusion, isolation and marginalisation.

It transpired from the theory as well as from an analysis of the data that a further problem inherent in interaction between the blind and the sighted world is that hidden assumptions underpin most of such interactions (Morris, 1991). All the participants reported that they had been treated in terms of such assumptions. Despite apparent evidence to the contrary, they have experienced being treated as if they are not normal, capable of nothing and consequently always in need of assistance.

The theory also revealed that, like other disabled people, the blind are subject to stereotyping in various ways (Clogston, 1990, in McDougall, 2006; Rowland, 1985). Some of the participants related that they have experienced being stereotyped as either pathetic and dependent, or, on other occasions, as super-heroes who should be admired. Also, some of the participants related that they are aware of and have experienced the stereotype that blind people, notwithstanding their abilities or skills, are unthinkingly exclusively linked to certain jobs or careers.

For the most, the participants in this study experienced being viewed and treated in terms of the above-mentioned as unacceptable; such treatment led to a range of responses from irritation and frustration to despondence, impotent rage and anger. Furthermore, in the light of the participants' negative responses to being viewed and treated in this way, the implication may be drawn that the participants were, at least at some level, aware of the fact that others' treatment of them is imbued with psychic investments; that it is, in some way, for the others' benefit.

In addition, complicating social interaction further, the analysis of the data revealed that the participants also experienced certain specific difficulties with spoken

communication and ordinary listening when interacting within a larger group. The participants related that they have experienced social uncertainties in terms of how loud to speak, whether he/she is being addressed, where the other person is and whether his/her companion has left him/her.

Most of the participants also reported that they have experienced the inability to make eye-contact within the social context as extremely problematic. They have reported that on account of not being able to make and maintain eye-contact, others ignored them or simply stopped talking to them. This clearly does not facilitate positive social interaction and, together with all the other factors that complicate interaction with others, negatively affected the social well-being of the participants. It transpired from the analysis that, for these reasons, some of the participants reported that they actually prefer communicating via the computer or other electronic media.

Given the above and the fact that blind people have to operate within the social arena amidst an essentially disablist world, the literature makes mention of blind people eventually suffering a loss of social adequacy. According to the theory, this loss of social adequacy may well be perceived by blind people as one of the most severe losses amongst the many possible losses that may constitute the personal experience of living with blindness (Carroll, 1961).

A surface reading of the data did not expressly indicate that the participants experienced a loss of social adequacy or, if they did, whether they felt it to be one of the most severe losses of blindness. However, most of the participants reported that they have experienced social difficulties of some kind and that such difficulties hampered effective social interaction with others. A closer look at what underpins their words revealed that in their dealings with sighted people, there was a preoccupation with how others viewed and treated them, and that others' perceptions and actions strongly influenced their general well-being. Therefore, any loss of adequacy regarding their interaction with the sighted world, if not the most serious loss, must at least by implication, be extremely important to the participants.

5.6.1.3 Personal independence

Blindness usually, but not necessarily, implies a loss of personal independence. Depending on individual circumstances, it can affect amongst other issues, mobility, career, finances, recreation and social relationships. The analysis of the data revealed that none of the participants directly mentioned that they had suffered a loss of independence in any particular area. However, most of the participants felt that independence was an important issue and that it is necessary for blind people to be as independent as possible.

It appeared from the literature that the issue of personal independence for blind people is more complex than meets the eye (French, 1993c). Like other disabled people, blind people live their lives under constant external and internal pressure to be normal, to be as good as everyone else, possibly even better. To be just like everyone else implies being at least as independent as everyone else. This is problematic; although everyone has their problems and limitations and is dependent on each other to some degree, non-disabled people's problems and limitations are regarded as normal and acceptable and thus they can ask for help from one another without feeling guilty or inferior. On the other hand, disabled people's limitations and problems are regarded as different and not normal, and they can only ask for help as long as the problem is not disability related (French, 1993c).

Furthermore, disabled people are expected to cope with their problems and limitations in a way not expected of other people; they must manage and overcome their disability. They are expected to be independent, to be normal and to play the disabled role. This often obscures the real problems they face and interferes in finding the best solutions. Even though giving and receiving help can greatly enrich human experience, all these pressures make accepting help difficult for disabled people (French, 1993c).

It was evident from the analysis (from a close reading of the participants' words) that they felt that they ought to be normal and therefore independent. It also appeared from the analysis that the participants in general regarded undue dependence as signifying a loss of freedom and autonomy, and that therefore asking for help may lead to feeling guilty or inferior. As pointed out in the literature (French, 1993c), such

pressures make accepting help difficult, yet like everyone else, the participants may need others' help from time to time. Consequently, the participants experienced mixed feelings regarding the topic.

Carroll (1961) explains these mixed feelings in terms of the fact that for the blind person two opposing forces are at work: the desire for independence and its freedom, and the desire for dependence and its protection. It is suggested that, ideally, an emotionally mature blind person ought to make peace with the fact that sometimes dependence might have to be forced on him/her. He/she may wish that it were different, and will accept it when necessary, but will not seek it when it is not. The problem, however, is that very few people have such maturity (Carroll, 1961).

In this regard, the participants experienced ambivalent feelings in relation to independence. One of the participants related (with a certain degree of vehemence) that he does not want to depend on others and that, in his opinion, blind people do not particularly need relationships with other people, certainly no more than anyone else. Yet, notwithstanding his evident need for independence, he also seems to realise that blind people cannot afford the luxury of eschewing sighted friends. He related that he made a particular point of including sighted people in his circle of friends. This was for the express purpose of assistance, in particular in the form of transport, even admitting that it does not bother him should such sighted people suspect his motives.

Generally though, from a reading of what lies beneath their words, it would appear that in the course of living with blindness, most of the participants have come to realise that total independence is not possible and that one has to learn to accept help from others, possibly resulting in a certain degree of dependence on such others. In this regard, one of the participants sensibly related that she has experienced that for practical reasons (that is, for the purposes of transport) it is 'good' to have sighted as well as blind friends.

A further issue raised in the literature is that often well-meaning people simply assume that disabled people want to be independent and that any help they could provide would inevitably be second-rate. It does not occur to people to ask disabled

people directly concerning this issue and such people often simply assume that they know what is best for disabled people (French, 1993c). The analysis of the data confirmed this point. Some of the participants related that others frequently attempted to assist them without asking them whether they actually needed assistance, or what kind of assistance was in fact required.

5.6.1.4 Visual appreciation of the pleasurable and of beauty

Although not expressly referred to by any of the participants, the lack of the visual dimension of pleasurable experiences is a factor to be considered in the lives of blind people. The visual component of people and things, including the sex object, is obviously not present for blind people. Although no one referred to this loss directly, and it is unknown if in fact it even constitutes a loss at all, one of the participants made a general remark that blind people sometimes tend to forget that they have a body at all. This occurred during a discussion on whether a blind person ought to marry a sighted person and in particular in regard to physical attraction. It is likely that the participant referred to his own experience in this regard.

The literature refers to the possibility that blind people may suffer a loss of physical integrity, a loss of wholeness, of being a complete person. This may be accompanied by feelings of not being physically attractive, of physical inadequacy, a sense of having 'lost' the body (Carroll, 1961). From a reading of the participant's remark, it might be speculated that he has experienced a feeling of being let down by the body, resulting in the body and specifically some of its needs, being ignored or overlooked.

Another participant also raised an issue related to the body and, in particular, the loss of the visual perception of the sex object. Whilst commenting on the issue of whether blind people should feel obliged to marry only other blind people, he remarked that it might be better for blind people to marry other blind people on account of jealousy within the relationship. He further claimed that jealousy is a major factor in the lives of blind people who marry sighted people because of the insecurity of the blind partner regarding the sighted partner finding others physically attractive and then straying.

Although the participant referred to above did not say that he was talking about his own situation, it can be deduced by his very vehemence that this may indeed be the case. Unlike the previous participant who related that blind people sometimes tend to forget that they have a body, this participant clearly has not forgotten this fact. He seems to be very much aware of his body and its 'loss'. It is evident that on account of his blindness, he keenly feels the loss of the visual perception of the sex object. Furthermore, by relating that this may lead to the end of the marriage and inasmuch as this relates to him personally, he indirectly conceded that this loss may negatively impact on his life.

With regard to visual beauty, it is obvious that blind people can no longer appreciate beauty visually. Whether this is a loss or how keenly it is felt depends on whether the person was born blind or lost their sight later in life, as well as their personal appreciation for beauty. This aspect was not under investigation in the study and no participant made direct mention of it. However, one of the participants, in weighing-up the merits of marrying a blind person versus a sighted one, remarked that he is glad that he married a sighted person because such a person is able to describe the beauty of the world to the blind partner. He also added that life would be difficult and dull without a sighted partner. This indicated that this participant is at least aware of this aspect of blindness and that this loss has had an impact on his life.

5.7 Conclusion

In summary, in this study, the meaning of the concept of disability was under investigation, with the focus on the real experience of disability as it applied to the nine participants living with blindness amidst a disablist world. The main argument was that the interactions between blind people and the sighted world are largely informed by hidden assumptions and that these assumptions may influence the way sighted people treat blind people. Further, the study argued that living with impairment amidst a largely disablist society may negatively impact on the emotional and social lives of some blind people.

The interpretation of the results was presented in terms of two broad areas: others' responses to blindness, as well as the participants' responses to others' treatment of them. In addition, the results were interpreted in terms of the personal experience of

living with blindness amidst a disablist society, including personal experiences in the areas of self-esteem and self-worth, social interaction, personal independence and visual appreciation of beauty.

From the analysis and interpretation of the data it can be concluded that sighted people's assumptions regarding blindness and blind people do inform their understanding of blindness and that this affects their treatment of blind people. Further, regarding the nature and effect of these assumptions, it appeared from the data that such assumptions are largely unconscious and reflective of underlying societal discourses regarding disability. In addition, it was shown from an analysis of the data that the attitudes of sighted people regarding blindness and blind people may be imbued with psychic investments. It also transpired from the data that living with blindness impacts, in various areas, on the social and emotional well-being of blind people.

In the last chapter, conclusions are drawn and a few remarks and suggestions concerning the future of disability issues are made.

Chapter 6: Conclusion

The experience of disability (in this case, blindness) was under investigation in this study. After an examination in terms of the medical and social models of disability as societal discourses underpinning the meaning of the concept, a need for recognising and acknowledging the real experience of disability emerged. It is clear from the analysis of the data collected, and more specifically from what the participants related in terms of others' treatment of them, that the real experience of blindness is indeed personal and includes accounts of personal difficulties related to living with impairment amidst a disablist society. The analysis revealed that the participants live their lives within a world where there are many hints of assumptions and stereotypes concerning blindness and that these are ever ready to be sparked and ignited at any mention of, or encounter with, blindness or blind people. The analysis indicated that this, in addition to the physical impact of living with impairment, left its mark on the emotional and social lives of the participants.

Although the real experience of living with blindness differed from person to person, the experience nevertheless had a definite impact, at some level at least, on the participants' sense of self and also on any exploration and expression of self, even if the participants made no direct mention of it. The literature clearly outlines the situation of blind people living amidst such a disablist world. The idea of disability is associated among other things with tragedy, inability, abnormality, dependence, helplessness, suffering and the experience of loss, leading to disabled people unthinkingly being linked to some or all of the above. This was borne out by what the participants related regarding the way others viewed and treated them.

Furthermore, the theory points out that disabled people are expected to feel a sense of loss and misery, yet they are often at the same time socially forbidden from articulating this in any way; they are compelled to be silent about substantial areas of experience for fear of being defined in terms of such experience, of having their identities contaminated by it (Watermeyer, 2009). For this reason, some of the participants attempted to hide their disability. Some made light of or minimised their disability, and others even engaged in attempts to deny it. According to Watermeyer (2009), many disabled people live inauthentically; they are precluded from being who

they really are, because they are not allowed to reveal and share with others difficult and painful parts of themselves, something that is their due by virtue of being human (Watermeyer, 2009).

Consequently, many disabled people (including blind people) regard the disproving of negative imputations as paramount, even more so than any exploration and expression of aspects of the self. The effect of this is that such blind people live only in terms of defining themselves in opposition to negative imputations. For them, it is essential to reverse such expectations and above all, to make sure that there is nothing in their behaviour to support any attribution of such traits to them. In the analysis of the data, this is demonstrated by the insistence of some of the participants that there is nothing wrong with them, that they can do exactly what others can do and in some instances even more, that they do not need other people or their help.

Blind people, like everyone else, should without penalty to their identity, be allowed to articulate and share with others their difficult and even shameful parts, as these constitute a substantial part of their life experience and of themselves. The intention of the present study was in part exactly that; it attempted to provide a safe space for the participants to share some personal meanings, inclusive of experiences of loss and personal suffering.

Although the participants freely revealed the difficulties they experienced at the hands of others, the data showed that most of the participants were reluctant to disclose directly their own intimate experiences of living with blindness and the impact that these had on their emotional well-being. This is a limitation of the current study; it was disappointing that most of the participants did not feel free to explicitly talk about experiencing personal difficulties, or about feeling loss of any kind or admitting openly that they have experienced suffering related to living with blindness.

Possibly, the reason for this could lie in not having used the right method to obtain the data, or not asking the right questions. The data in this study was collected via email contributions. Although responding via email may have contributed to easier self-expression, in that the usual stresses associated with face-to-face

communication were avoided, it may also have restricted the participants' ability to express themselves on a deeper level.

In terms of the method for data collection, both focus groups and face-to-face interviews were considered and rejected. This was primarily for practical reasons. Because there is a relatively small community of blind people in South Africa, using individual interviews or a focus group would have required all the participants to have been living in the same town or city. As mentioned above, most blind people are likely to have needed transport to the venue and this may have been a time-consuming and costly undertaking. In addition, a focus group would have had implications for privacy and confidentiality as it would have been likely that the participants knew each other.

A reading of the literature indicated, however, that it is important to find a method of collecting data that best facilitates effective communication with the participants (Creswell, 2009). Therefore, if a focus group had been utilised or face-to-face interviewing employed, the researcher might have established better rapport with the participants and might have been able to guide the process towards probing deeper issues.

On the other hand, although face-to-face interviewing allows the researcher to manipulate the process, asking questions, listening to responses, prompting for more information and guiding the direction of the conversation (Creswell, 2009), at the same time, in a face-to-face interview, the blind person may experience difficulty with making and maintaining eye contact. The problem of maintaining eye contact is particularly relevant in the focus group context as various social difficulties may inhibit open communication; these include not knowing when to speak, who is present at the moment of speaking, how loud to speak and the inability to read others' responses to what is being said (Rowland, 1985). Although this may not necessarily have been the case if the researcher had conducted the focus group herself, the cost implications of physically gathering the participants together was insurmountable.

Lastly, telephonic interviewing was considered but rejected in favour of email communication. All of the participants, as well as the researcher, were familiar and comfortable with using a computer; thus, email contributions were utilised as the method of collecting data which best facilitated effective communication. Email communication also allowed the participants to respond without the pressures of direct telephonic contact, which could have put them on the spot and not given them the chance to reflect on their answers. Being able to respond via emails allowed the participants to think carefully before making their contributions.

Thus by using different methods and by asking the right questions it may have been possible to encourage the participants to reveal more of their personal meanings at a deeper level. However, the participants' reluctance to expressly reveal deeper meanings may ultimately have been due to the fact that they may have felt that owning up in any depth to having experienced any of the above, may in some way have led to being defined in terms of these. It may have felt dangerous to share their true feelings, even in this context.

Having discovered that there existed a certain reserve in articulating the real experience of living with blindness, possibly because of all the factors raised above, it appears not to have been enough simply to provide a space to share some personal experiences of living with blindness. As the analysis of the data showed, the real experience of disability is partly interactionally constructed; the blind and the sighted are both implicated. A more interactive approach may therefore be needed. Future research might focus on attempting to create some kind of forum for dialogue between blind people and the sighted world.

This would doubtless prove to be no easy task, as it is not simply a matter of attempting in some way to educate the general public regarding blindness in order to change their attitudes. As it is, the literature showed that disability-awareness strategies have not so far been particularly successful in bringing about change in people's attitudes or in disabled people's situations (French, 1993a).

It is suggested that it is not enough merely to make others aware of what it is like to live with impairment. In fact, for a disabled person to frequently refer to the matter

may even lead to adverse effects; such a person may thereby be unthinkingly linked with hidden assumptions and associations regarding disability or viewed as always complaining or as being preoccupied with personal disadvantage. In order to bring about even a modicum of change in people's attitudes or in disabled people's situations, it is suggested that some shift of perspective has to take place. To bring about such a shift, disabled and non-disabled alike need to choose to take part in the story of each other's lives. Furthermore, by the sheer virtue of being human, everyone ought to be afforded an opportunity to authentically interact with others.

The social media, which is very influential today, is particularly suitable for this purpose. Communicating in such an online environment avoids the prejudices that often slot unthinkingly into place when disability is encountered in the social arena. Within a virtual social environment the body can be absent, making it possible for people to separate their physical bodies from their social identities. This enables them to interact without the usual relational barriers associated with interaction between disabled people and others (Goggin & Newell, 2003, in Stadler, 2006). Within a virtual social environment, people can form relationships irrespective of age, race, gender and ability, and are able to communicate with each other across any distance, creating online communities that are not limited by geographical location (Stadler, 2006). This may facilitate easier interaction between disabled people and others.

Future research may focus on exploring aspects of such on-line dialogue between blind people and the sighted world. Furthermore, regarding the way people experience blindness in particular, future research using different methods (such as face-to-face interviewing, a larger sample and a wider range of participants) may facilitate a more in-depth exploration and understanding of the real experience of disability. Such research might employ individual interviews with blind people, exploring their daily experiences of being blind in order to access a greater understanding of the embodied nature of blindness. Future research might also explore issues related to body image and physical integrity, especially in relation to the age of onset of blindness, the link between social difficulties and self-image and whether or not blind people understand their experience of blindness in terms of loss and suffering, as suggested by the present research.

Although the task at hand may seem daunting and the issues raised in this study may be disturbing, even unpalatable, it is suggested that disabled people and non-disabled people alike should not allow this to deter them from forging ahead and facing the challenges that disability presents to society and to those who are viewed as disabled.

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Appendices

Appendix A – Ethical clearance letter



23 January 2013

Mrs Maria CW Michell (211560289)
School of Applied Human Sciences - Psychology
Pietermaritzburg Campus

Dear Mrs Michell

Protocol reference number: HSS/0020/013M
Project title: Constructions of disability: An exploration of the embodied experience of blindness

APPROVAL

I wish to inform you that your application has been granted Full Approval.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

.....
Professor Steven Collings (Chair)
/ms

cc Supervisor: Dr Bev Killian
cc School Admin: Ms B Jacobsen

Professor S Collings (Chair)
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Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

INSPIRING GREATNESS



Appendix B - Letter to gatekeepers

This letter was emailed to the SA National Council for the Blind, Tape Aids for the blind and a retired chairperson of the blind workers association.

My name is Marietjie Michell and I am a blind Master's student in the School of Psychology at the University of KwaZulu-Natal. I intend to undertake a study to investigate what it means to be disabled within one's community. I was motivated to undertake this study because as a disabled person myself, I have observed that most people are unfamiliar with what it means to be disabled. This can make them uncomfortable with disability and disabled people, and could lead to the avoidance, exclusion and eventual marginalisation of disabled people.

With this study, I want to make people aware of what it means to live with disability in order to further a better understanding of it for my participants, for myself, as well as society at large.

The idea is for those who read the study to vicariously experience the everyday challenges that we encounter in living with a disability. Hopefully, the study will provide a lens through which they can view and understand our world. I argue that a better understanding of what it means to be disabled may further the acceptance and inclusion of disabled people, thus creating a better society for everyone.

I will need three to nine blind participants for the study. The research will entail initially asking the prospective participants to email me a short paragraph about themselves. After receiving these short contributions, I will invite three to ten blind people to take part in the research. These participants will be invited to take part on the basis of their being comfortable to talk about the experience of living with blindness and having time to devote to the research.

After receiving the initial short contribution, I will ask the participants to respond to the following questions: Describe an ordinary day in your life; tell me about your social life; what have been your experiences in terms of social interaction?

Furthermore, I will also invite the participants to raise topics of personal interest and to suggest further questions and issues for exploration.

As I will ask the participants to respond to me by means of emails, they must therefore all have access to 'JAWS' or other assistive technology for the blind.

If you know of anyone that might be interested to take part in this research, could you please supply me with a list of names and email addresses of such prospective participants. Upon receiving such a list, I will contact all the prospective participants by email, introducing myself, explaining to them what I intend to do, and inviting them to email me a short paragraph about themselves.

If anyone agrees to participate in this research, I will explain to them that their participation is voluntary and that they are not being forced to take part in the study. The choice of whether to participate is theirs alone. Further, I will make it clear to them that if they agree to participate, they may stop at any time and discontinue their participation. If anyone does not want to participate or withdraw at any stage, there will be no penalties and such a person will not be prejudiced in any way.

I will inform them that they may choose at any time during the research not to answer certain questions or engage with certain issues. I will assure the participants that if I ask them a question or suggest a topic for discussion that makes them feel sad or upset, we can stop immediately. Should such issues or problems arise during the research, I will provide the name and number of people that would be able to assist such participants. They may contact the South African National Council for the Blind at 012 452 3811.

I will assure the participants of complete confidentiality. I will not record any names. Each participant will be given an anonymous user name. No one will be able to link the participants to their email contributions. Only I will have access to the information. At the end of the research, once data capture and analysis are complete, I will delete all the emails relating to the research.

If you have any questions about this research you may contact my supervisor, Dr. Mary Van der Riet at the University of KwaZulu-Natal in Pietermaritzburg on 033 260 6163.

Should you have a complaint about any aspect of this study you may also contact the ethics committee of the University of KwaZulu-Natal on 033 – 2605111.

Feel free to contact me at any time to discuss this research. My details are: Email: XXXX

Many thanks,
Marietjie Michell

Appendix C - Letter to prospective participants inviting them to submit a short paragraph about themselves.

My name is Marietjie Michell and I am a blind Master's student in the School of Psychology at the University of KwaZulu-Natal. I was given your name and email address by.....[name of gatekeeper], as a prospective participant in my research.

I intend to undertake a study to investigate what it means to be disabled within one's community. I was motivated to do this study because as a disabled person myself, I have noticed that most people are unfamiliar with what it means to be disabled. This can make them uncomfortable with disability and disabled people and could lead to the avoidance, exclusion and eventual marginalisation of disabled people. With this study, I want to make people aware of the nature of disability, in order to further a better understanding of it for my participants, myself as well as society at large.

The idea is for those who read the study to vicariously experience the everyday challenges that we encounter in living with a disability. Hopefully the study will provide a lens through which they can view and understand our world. I argue that a better understanding of what it means to be disabled may further the acceptance and inclusion of disabled people, thus creating a better society for everyone.

I will need three to ten blind participants. The research will entail responding by email to the following questions:

- Describe an ordinary day in your life.
- Tell me about your social life; what have been your experiences in terms of social interaction?

I will also invite you to raise topics of personal interest and to suggest further questions and issues for exploration.

If you are interested to take part in this research, could you email me a short paragraph about yourself? After receiving these short contributions, I will invite three to ten blind people to take part in the research.

If you have any questions about this research you may contact my supervisor, Dr. Mary van der Riet, at the University of KwaZulu-Natal in Pietermaritzburg on 033 260 6163.

Should you have a complaint about any aspect of this study you may also contact the ethics committee of the University of KwaZulu-Natal on 033 2605111.

Please let me know whether you would like to be part of my research. Feel free to contact me at any time to discuss this research.

My details are: Email: XXXX

Many thanks,
Marietjie Michell

Appendix D - Letter to participants

Dear (name of participant)

After receiving your short paragraph, I would like to invite you to take part in the research. Could you please share with me your thoughts by answering the following questions:

- Describe an ordinary day in your life.
- Tell me about your social life; what have been your experiences in terms of social interaction?

You can respond as often as is convenient for you and your contributions may be of any length. I would, however, encourage you to give as full as possible a description of your experiences, including your thoughts, feelings, images, sensations and memories.

I would also like to invite you to raise topics of personal interest and to suggest further questions and issues for exploration, which I will email to the other participants for discussion.

I would like you to understand that your participation is voluntary and you are not being forced to take part in the study. The choice of whether to participate is yours alone. You may stop at any time and discontinue your participation. If you do not want to participate or withdraw at any stage, there will be no penalties and you will not be prejudiced in any way.

You may of course, choose at any time not to answer certain questions or engage with certain issues. If I ask you a question or suggest a topic for discussion or if we have a conversation that makes you feel sad or upset, we can stop immediately. In such a case I can give you the names and numbers of people who are able to assist you. You may contact the South African National Council for the Blind at 012 452 3811.

You may be assured of complete confidentiality. I will not record your name. Each participant will be given an anonymous user name. No one will be able to link you to your email contributions. Only I will have access to the information.

In order to ensure that your name is not linked to the research, I will not ask you to sign an informed consent form; sending me the short paragraph and any further contributions will be enough to confirm your consent to participate.

At the end of the research, once data capture and analysis are complete, I will delete all the emails relating to the research.

If you have any questions about this research you may contact my supervisor, Dr. Mary van der Riet at the University of KwaZulu-Natal in Pietermaritzburg on 033 260 6163.

Should you have a complaint about any aspect of this study you may also contact the ethics committee of the University of KwaZulu-Natal on 033 - 2605111

Feel free to contact me at any time to discuss the research. My details are: Email: XXXX

Many thanks,
Marietjie Michell